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A New Ethical Model for The Analysis of Care for Refugee Women Who Experience Female Genital Cutting

Sharon R. Higginbothan

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A NEW ETHICAL MODEL FOR THE ANALYSIS OF CARE
FOR REFUGEE WOMEN
WHO EXPERIENCE FEMALE GENITAL CUTTING

A Dissertation

Submitted to the Center for Healthcare Ethics

McAnulty College and Graduate School for Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Sharon R. Higginbotham

December 2015

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Sharon R. Higginbotham

2015

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ABSTRACT

A NEW MODEL FOR THE ETHICAL ANALYSIS OF CARE FOR REFUGEE WOMEN WHO EXPERIENCE FEMALE GENITAL CUTTING

By

Sharon R. Higginbotham

December 2015

Dissertation supervised by Dr. Henk ten Have, M.D., Ph.D.

The United States is rapidly becoming a location for refugee women who are migrating from countries that embrace different and distinctive practices. One such practice is Female Genital Cutting/ mutilation (FGC/m). FGC is a medical procedure that alters the natural structure and functioning of the female body. It is also a cultural tradition and custom. Until recently, worldwide studies estimated that approximately 80 to 140 million women have undergone FGC and that 228,000 of those women live in the U.S. However, the estimate of women and girls in the U.S. living with or at risk from FGC has grown from an estimated 228,000 to 513,000.

Globally, FGC has raised justifiable concerns, particularly when the procedure is performed without consent. As female refugees migrate from FGC/m communities to a non-FGC/m reality, women not only bring their customs, beliefs, and values – they bring their health

care needs. FGC is associated with alleged health consequences. A major challenge, then, for health care in the U.S. is how to provide care for this group of women whose native ethos is countercultural to the practices in the United States.

When exploring FGC through a medical lens, FGC is considered an immoral practice that will result in harm and the need for healthcare. Conversely, however, when FGC is observed through the lens of respect for cultural diversity, it is not merely a negative construct, rather, it is a traditional cultural practice embraced by women who choose. The right for individuals to participate in their culture is a human right.

Since FGC is a surgical intervention, care is needed for women who choose. FGC is relatively novel and unfamiliar in the United States. In that way, to provide care is realized through the Georgetown and the Global bioethics frameworks from which FGC is ethically examined. An investigation through the lens of FGC garners what is needed to construct a specific model of care. Therefore, the title of this dissertation was changed from “Female Genital Cutting: What Should Care Be For Refugee Women Experiencing Female Genital Cutting,” to “A New Model for the Ethical Analysis of Care for Women Who Experience Female Genital Cutting.”

DEDICATION

This dissertation is dedicated to my daughter, and to women globally who embrace a diversity of rich cultures in which they have the right to participate and practice.

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To my mother whose love, and wisdom empowered me for one of hardest, grueling, most engaging and rewarding labor's of love ever, my sisters, for your love, and prayers, and my daughter whose love, sacrifice, and care sustained me. To my inner soul circle, for their emotional and spiritual support never waived, and didn't let me quit. I am very grateful to my

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Chapter 1: Introduction

I. Understanding Female Genital Cutting (FGC)

The World Health Organization defines FGC as “partial or complete removal of the female external genital or other injury to the female genital organs for cultural or non-medical or therapeutic reasons.”¹ It is estimated that there are between 100 and 140 million women and girls in the world who have undergone FGC and it is anticipated that each year 3 million girls are at risk of undergoing the procedure. FGC is deeply embedded in culture and is practiced in more than 28 countries in Africa, Asia, and the Middle East. FGC is regarded as a way of life. There are some countries in Africa that experience the highest estimated prevalence of FGC in the world.² In addition, certain countries have become war zones and are unsafe for people to live on a daily basis. Therefore, families leave their homes, which are often within FGC communities, and migrate to safer environments that are a non FGC reality, namely the United States. Women who migrate from their country of origin find ways to integrate their way of living into their current environment. In doing so, not only do they bring their customs, beliefs, and values, but they also bring their health care needs. One problem for women from different cultures and traditions, and a focus of this dissertation, is how they continue to practice the rituals of their culture when their cultural traditions include customs that are often in conflict with the host country.³ One such customary practice is Female Genital Cutting (FGC). For women not to engage in their cultural customs and practices, but rather to abandon these cultural traditions, has consequences that include rejection and shame from their families and communities. The magnitude of this kind of communal pressure experienced by these women, and the obligation to practice cultural customs outside their indigenous country, is quite persuasive.⁴ This predicament makes it probable that women will find alternative ways to assimilate the cultural

customs to which they are familiar. Therefore, attempts to practice FGC underground are likely to occur, contributing to the danger and injurious nature of the practice as well as the need for care. What model of care will be sufficient for women experiencing FGC will be explored and developed in chapter 7.

II. Historical Background and Overview of FGC

While there is much debate about the beginning of the practice of female circumcision, scholars, cannot not agree on its beginnings. Not only is there disagreement about the origins of both male and female circumcision, there are diverse opinions about its genesis. After an examination of the historical scholarship on female circumcision (FC) it is difficult to articulate the origins of FC without an investigation on the history of male circumcision. According to some scholarship, the beginning of Female Circumcision, (the term used in the historical literature), FC is rooted in antiquity, and preceded both Christianity and Islam.⁵ The genesis of male circumcision, however is attributed to particular groups of Australian Aborigines who practiced “totemic genital surgeries” but the exact origin of the practice is unknown.⁶

The earliest written accounts of circumcision are in the context of religion. Circumcision is referenced and characterized in the Old Testament. Circumcision, namely male circumcision was and remains a practice in the Jewish tradition. An example of the historical account of male circumcision in Judaism reveals that there are representations of temple priest “in the act of circumcision on young noblemen.”⁷ Circumcision was done on infant boys and symbolized ones faith. The mark of circumcision denoted their identity to the community of God. Another feature of male circumcision was that infant circumcision distinguished Israelite males from those males

who were not circumcised “a concern that grew acute during the Babylonian exile.”⁸

Interestingly, the historical accounts of circumcision reveal that circumcision was associated to the notion of class, as the surgery was afforded only to the upper echelon of priests.

Male circumcision was linked to health, and particularly maintaining health. The surgery was aimed at preventing disease, a rationale attributed to the reasons and rationales for Female Genital Cutting (FGC) found in current literature on the subject.⁹ While the surgery was recognized medical in nature, male circumcision “failed to find its way into classic Egyptian medical text.”¹⁰ Even though circumcision did not find its way into classic Egyptian medicine, “preventing excessive harm to the patient and producing a satisfactory aesthetic result” was of concern to those performing the surgery.¹¹ Furthermore, preventing harm and an aesthetically acceptable and pleasing outcome are both current topics in the FGC scholarship. For ancient Egyptians and those who emulated the Egyptians, circumcision was not only a matter of preventing disease but it was also connected to hygiene, morality, and spiritual and intellectual refinement. Egypt incorporated and preserved the practice of circumcision as a religious and social custom. It is here that scholars illustrate the trajectory of circumcision to the West and note “with respect to its source [circumcision] is a tributary into the mainstream of Western culture from the recesses of ancient Egypt.”¹²

It is reported that Female Genital Cutting (FGC) or circumcision, as it is referred to in the historical literature, could be as ancient as its counterpart male circumcision. Some writers explain that the beginning and the meaning of FGC are as ambiguous and puzzling as male circumcision. Much of the scholarship on FGC illustrates that female circumcision (FGC) dates back to at least 2000 years. The first known accounts of the FGC are traced back to the Greeks in the fifth century B.C. According to Hosken, “archeologist found well preserved mummies that

established clitoridectomy and infibulation, (the most severe of the procedures) had occurred.”¹³ Also tracing the beginning of what was referred to as in history as circumcision one scholar further writes regarding the history of traditional practice, “Herodotus mentioned this custom specifically, informing us that the Phoenicians, Hittites and the Ethiopians as well as the Egyptians undertook the practice” of FGC.¹⁴ Similarly recorded in the historical scholarship Strabo, a greek historian and geographer found evidence of the FGC among Egyptian women in the early first century A.D. Other scholarship notes that circumcision was a ritual practice that effected both male and female. Historically, the procedure was known as female circumcision (FC) and was seen as simply a female counterpart to the male practice of circumcision. In thinking about what circumcision means, scholars note that it was “partly about purification” as purity was an “Egyptian obsession.”¹⁵ It seems to follow then that in the place where circumcision of females is most pervasive that one of the rationales for the practice is intimately associated with purification and purity as it was in cultural antiquity. As its male circumcision counterpart, female circumcision was linked to both religion and medicine where the main rationale was to purify, physically and spiritually. It is important to note that the scholarship on FGC continues to regard religion as a rationale for the traditional practice.

Important to the history of circumcision is the political dialogue that seems very much connected to the history of FGC and to the language used to describe it. Linked to the political discourse is the conversation about what to call the procedure and is without question central to the debate.¹⁶ The argument on terminology is why society both tolerates the practice and at times defends it.¹⁷ It is important to note that the debate on what to call FGC is linked to the status of women in society. Nevertheless, the term female circumcision is but one term used to describe

the procedure and specifically describes the removal of tissue around the genitalia of women and girls.¹⁸

In the debate over terminology the juxtaposition of male and female circumcision surgeries is used. Circumcision for females and males alike are associated with an initiation into adulthood. The term female circumcision is used in most African communities and is “a source of significant controversy among critics of the practice” particularly in the West.¹⁹ Female Genital Mutilation (FGM) as some refer to the practice, “is a name given to several different traditional practices that involved the cutting of female genitals.”²⁰ The scholarship illustrates that there are also other terminologies used to describe the practice of female circumcision.

Other terms used to describe the practice includes, female surgeries, female traditional surgery, and female gentile cutting and excision. One term of fierce debate, and often used to refer to the surgery is “female genital mutilation.”²¹ The literature concerning the history of the practice notes that it was the Hosken’s Report that “popularized the expression female genital mutilation,”²² and made it available to the media and opinion leaders who were influential in communities and groups who opposed the practice. While the literature describes the term mutilation as a term that is politically charged, it was adopted by the World Health Organization, (WHO) Research, Action, and Information Network for Bodily Integrity (RAINBO) and other organizations whose aim is to eradicate the practice. The scholarship illustrates that the reason for the use of the term mutilation by those who want to abolish the practice is the term “mutilation” technically depicts the practice and makes clear the harmful consequences associated with the practice.²³ One scholar writing about FGC asserts that the term mutilation “emphasizes the harm and makes it a very effective advocacy tool.”²⁴ As it relates to what to

call the traditional practice one writer observes that “there has been much misinformation perpetuated through the use of different terms.”²⁵

Not everyone, including scholars writing on the subject, agrees that mutilation is the most appropriate term to apply to the practice. Those who object to the use of mutilation describe FGC the term as “offensive, criminalizing, psychically mutilating, and even shocking to communities that perform the practice.”²⁶ A further analysis of the term mutilation finds that the term “projects a double standard by the West” by publicly disapproving and denouncing the practice without condemning the West’s obsession with the many body enhancements ideology and surgeries.²⁷ Another problem with the use of the word mutilation is that the word implies excessive judgment and promotes an insensitivity toward women who have undergone the procedure.

In addition one writer notes that using the term mutilation strongly suggests and infers “intentional harm and evil intent,” an accusation denied by those involved in the traditional custom.²⁸ The scholarship notes that using the term mutilation is rejected by “insiders” (those in Africa who embrace the traditional practice, particularly women) and is viewed as a biased term constructed by Western feminist and Western hysteria. Some scholars write that to use the term mutilation is to “imply that all of the surgeries associated with the practice of FGC are mutilating.”²⁹ According to the literature on FGC and specifically the types associated with FGC, Type I, called circumcision is not mutilating and is reported to be the least invasive of the surgeries. On the other hand however, to employ the term “circumcision” to describe all of the surgeries that are characteristic of the practice affords the reader to liken FGC to the male account of circumcision. Relating female circumcision to male circumcision is what some

scholars call a “false analogy” and it gives the wrong idea and impression of FGC particularly due to the differences of the surgeries and the level of harm rendered to each type of surgery.³⁰

The World Health Organization (WHO) groups FGC into four categories.

Type I, clitoridectomy, involves removing of the prepuce or the hood with or without excision of parts or all of the clitoris. Type I is called circumcision by some scholars writing about the subject and note that Type I can authentically be called circumcision. Efua Dorkenoo describes that Type I; circumcision can accurately be described as female circumcision, as it is the one surgery that is “identical to male circumcision.”³¹ The literature on FGC however includes all types of genital surgeries including the most invasive procedure and brands them all as female circumcision. In spite of this observation, various countries in Africa do not regard Type I, circumcision as “genuine circumcision.”³² This observation may be a factor in why the rate of Types II, III and IV are most common in some countries in Africa. For instance, Efua Dorkenoo describes Types II through IV surgeries as mutilation. She further illustrates that the equal of these surgeries to male circumcision biologically is “various degrees of penisectomy.”³³

Type II; excision removes the prepuce or hood and the clitoris at the same time, with partial or or total removal of the labia minor. Type II; excision accounts for approximately 80 percent of women who undergo the surgery, and is at times referred to as intermediary circumcision. Type III; infibulation removes part or all of the external genitalia. The clitoris, labia minor, and parts of the labia majora are removed. Tight stitching after the infibulation narrows the vaginal opening leaving a small opening for urine and the menstrual flow. Infibulation is described as the most extreme of the surgeries.

Type IV, is referred to as unclassified and includes all other procedures. Some of the procedures include for example, pricking, piercing, or being cut, particularly with a V shape.

Type IV includes all vaginal decorating. It is important to note that the literature reveals that these procedures are not exhaustive. When discussing the categories and types of circumcision it is helpful to include other names found in the historical literature on FGC. For instance Type I (circumcision) is also referred to in the Islamic culture as “sunna.” Type II; (excision) is called Khafd. Type III; (infibulation) is also known as “pharaonic circumcision” and this type was thought to be practiced during the Pharaoh dynasties in Egypt.³⁴

A. Prevalence of FGC

It was from an early beginning that the ritual practice of FGC spread to parts of Africa, the Middle East, Asia, and Latin America. The scholarship on the prevalence of FGC illustrates that the traditional practice continues and spreads due to the “ethnic, cultural, and religious affiliation of neighboring tribes who may live in different countries.”³⁵ An examination on the scholarship on the prevalence of FGC describes that another reason for its prevalence is that there are “several paradoxes in the reasons behind the practice and perhaps there is a hidden agenda as it pertains to women” who embrace and undergo the surgery.³⁶ For example, some of the literature written from a Western viewpoint on FGC does not reflect the idea that there are women who embrace female circumcision. This acceptance and positive acknowledgment of the practice can be attributed to the pervasive nature of the traditional custom. While some women agree that the procedure is painful, they further note that there is value in FGC and that circumcised genitalia “are considered normal.”³⁷ The value of FGC is connected to their beliefs and to their cultural customs.

It is estimated that approximately 100 to 140 million women worldwide have undergone FGC/c and that most girls who undergo the procedure live in Africa. It is additionally recorded that 228,000 women living in the U.S. have experienced FGC. There are countries in Africa

where the prevalence is more pronounced than other places. In addition, some countries practice one specific type of FGC, while others practice a combination of the surgeries. For example, in Egypt 97% of the women are circumcised. 72% have undergone Type II, (excision) 17% Type I (clitoridectomy) and 9% Type III (infibulation). In Somalia 98% of the women have Type III circumcision. On the other hand, in Uganda and the Democratic Republic of Congo, 5% of the women are circumcised with Types I and II. While the prevalence of FGC persists in Africa, the traditional practice occurs in various parts of world. Other geographical areas where FGC is practiced is in the Middle East and Western Asia. FGC is practiced in ethnic groups in Yemen, India, Israel, Saudi Arabia and Pakistan. There are increasing numbers of women who have experienced FGC/c found in Europe, Canada, Australia, New Zealand and the United States, primarily among immigrant women from countries in which it is practiced.³⁸

B. Reasons and Justifications

The most prevailing reasons and rationales associated with FGC can be found in the historical context of circumcision, namely male circumcision. The reasons for both male and female genital circumcision can be linked back to its origins. One example of the basis for circumcision attributed to the history and found in the more contemporary literature, is the medical rationale for circumcision. Currently there is fierce debate that the surgery serves no medical benefit. Historically, however the surgery was linked to prevention of diseases. The most common rationale that typically justifies circumcision is attributed to religion, a reason that some scholars writing about FGC disagree. Since the traditional practice is firmly established within the context of culture, ethnicity, and geographic location, the reason and rationales for the practice are as diverse as the places where the custom is practiced.³⁹ Justification for the practice

depends on an entire belief system not just one single factor, and the belief system that is attributed to FGC is properly placed in the historical context of the practice.⁴⁰

The World Health Organization (WHO) highlights four categories that illustrate rationales and reasons for the FGC. These include, 1) socio-cultural, and conformity 2) hygienic and aesthetic, 3) spiritual and religious and 5) psycho-sexual.⁴¹ Interestingly, the reasons and rationales cited by the WHO are parallel to those reasons attributed to male circumcision. This parallel affirms the embedded nature of ritual and tradition, culture, values and beliefs over time. Women who have both experienced FGC and who have daughters who are circumcised have very compelling reasons for the procedure.

An example of these reasons is illustrated in field studies conducted that highlight two main reasons women for circumcising girls. The first reason noted is that the practice reduces a women's sexual desire, thus preserving the young girls virginity until she is married.⁴² In Africa, a circumcised female is a prerequisite for marriage. Marriage is associated with security and security with the economic nature of the traditional practice. Other scholarship on FGC offers that circumcising girls is used as a way of protecting young girls against, namely rape, a reason that is not often fully investigated.

The second reason for circumcision given by the women who were interviewed is that circumcision works as a “catalyst to speed up a woman's full achievement of her femininity.”⁴³ Concerning femininity, in some parts of Africa their belief system is one that suggests that the clitoris grows to the size of a male organ, an idea associated with the notion of aesthetics. One reason for the aesthetic viewpoint is that some women in Africa describe their genitalia as ugly and look similar to that of men. It is reported that having genital modification (FGC) not only beautifies the genitalia to look more feminine, but the surgery purifies the female genitalia. The

idea of purity, a rationale also linked to the surgery, is that the larger the clitoris the “dirtier and uglier it is. The state of being uncircumcised was termed dirty and had to be washed away.”⁴⁴ It is important to note here that both purity and aesthetics are reasons attributed historically to circumcision. In the historical literature on the FGC, hygienics is associated with the idea of purity, a notion embedded in the early Egyptian culture. Hygienics and purity are named as primary reasons for circumcision of both males and female. While most women agree that the procedure is painful they embrace circumcision as a rites of passage to being a women.⁴⁵ Circumcision then serves as a way for women to embrace their femininity while beautifying the genitalia, a third reason for circumcision highlighted also by WHO.

Religion is one of the major influences attributed to FGC. Religion is credited to the origins of the both male and female circumcision and the transmission, prevalence and persistence of FGC. Religious beliefs are also one of the main influences that shapes social culture and social norms. It is connected to social conformity and certainly to ones value system. When linking FGC to religion, one scholar describes that “religion is one of the reasons consistently given for performing the practice but is also a strategy for addressing the issue.”⁴⁶ In a study focused on why women practice female circumcision, the study highlights that 90% of women report that religion influences their decision for engaging in the practice.

FGC is embraced as a religious ritual surgery and it also meets a religious requirement. According to some of the scholarship this religious requirement is most dominant in the Muslim faith. Conversely, however other literature notes that FGC “is not a practice required by the Koran” and questions the association of FGC to Islam.⁴⁷ The argument used to question the relationship between the Muslim faith tradition and FGC is that certain types of female circumcision, for example clitoridectomy and infibulation existed before Islam. Further

examination regarding religion as a rationale for FGC describes that the surgery is embraced by many faiths including Christianity. The scholarship however illustrates that there is uncertainty of the religious mandate in both Christianity and Muslim faith traditions.

It is important to note that there are other reasons assigned to FGC. For instance, Rahman and Toubia include other factors when identifying reasons for the practice which include 1). a rite of passage for childhood to adult hood 2) the need to control a woman's sexuality. 3) a cultural practice that has religious identification. 4) social conformity. Social conformity is a concept forwarded by much of the scholarship on FGC. It is argued that the FGC aids to preserve a place in community. It ensures acceptance in the community which has a compellingly strong influence, a notion that is expanded in the chapter on culture.

C. Health Consequences attributed to FGC

One of the most fiercely debated topics in the discourse concerning FGC is the discussion on health consequences and potential health risks caused by FGC. The health consequences associated with the practice are at the heart of the debate and present serious ethical dilemmas and queries. There are both physical and psychological complications associated with FGC. Some of the scholarship notes that there are also neurological consequences of the surgery. An investigation of the literature on health consequences describes both short term and long term complications.⁴⁸ It is important to note here that some of the research on FGC does not reflect which type of circumcision is associated with specific health risks and implications, rather the literature reflect that there are “possible” immediate complications for all types of circumcision.

The short term consequences that are linked to the FGC include severe pain, bleeding and shock from the intense pain. If the bleeding extends over a long period of time it can lead to

anemia and hemorrhage and if not controlled the excessive bleeding can lead to death. Other potential negative health implications are risks of infection such as HIV/AIDS, hepatitis B and C. The long term complications are associated more often with Type III, infibulation. These long term outcomes include difficulty with menstrual flow and urination, both which can cause infections. Untreated urinary tract infections can “ascend to the kidneys and bladder potentially causes renal failure septicemia which can lead to death.”⁴⁹

In some cases, Type III can cause damage to the sexual organs. Other complications attributed to the surgery and particularly Type III are painful intercourse, obstetrical complications, infertility, and dermoid cysts. The scholarship notes that all forms of FGC are alleged to be linked to diminished sexual pleasure, an allegation that is rejected by women who have undergone the surgery.⁵⁰ It is important to note however that scholars writing about FGC and the health consequences of the surgeries describe Type I (circumcision) as the “mildest type of the surgery and is the one surgery most associated to male circumcision.”⁵¹ Much of the health risks that are associated with the surgeries result from unhygienic circumstances. One example of the unhygienic conditions described in the scholarship is the use of dirty instruments. Often the unsterilized instruments are knives, razor blades, scissors, thorns and pieces of glass.⁵² Some of the scholarship especially characterizes un-sterilized to mean that instruments are used over and over again, without sterilization, a reason attributed to the high rate infection. Other reasons associated with the health risks are the dismal lack of medical treatment, substandard medical treatment and care available to women after the surgery is performed.⁵³ Health professionals are often unfamiliar and do not have the knowledge necessary to treat and care for women who undergo the surgery.

It is critical to note that the literature on the health consequences of FGC is abundant, and some scholars argue that it is one sided and unbalanced as there are opposing points of views. The conflicting viewpoint of the literature concerning health consequences is that the volume of literature on FGC and the health consequences is a dramatization of western views regarding FGC that frame the health consequences in such a dismal light.⁵⁴ This is not to say that women undergoing the procedure have not experienced negative health consequences as is the risk with all surgeries. The potential outcomes must be examined in a larger context that includes an ethical analysis of care for women undergo the surgeries.

D. Efforts to Eradicate

One of the engines that has fueled advocacy efforts to eradicate the practice of FGC in Africa and in the West was the 1995 opinion piece printed in the New York Times. This article set the dominant and unbalanced discourse in Western media. The scholarship however, notes that the movement to abolish FGC started in the early 1980's and that it was the Western media that sensationalized and created hysteria regarding the practice.⁵⁵

Despite rigorous attempts and strategies to eradicate the traditional practice, FGC still exists and persists throughout most parts of the world. The persistence of FGC indicates the resistance toward strategies to curb or eradicate FGC, however eradication remains a major theme in the FGC debate.

Historically, the effort to eradicate FGC was the result of a WHO seminar on “Traditional Practices Affecting Women and Children” held in 1998 in Khartoum, the Republic of Sudan. The recommendation made in the general assembly regarding FGC was to “adoption of clear national policies for the abolishment of female circumcision”⁵⁶ One major component of the strategy was education. The education about FGC particularly the health consequences resulting

from the surgeries, were focused toward practitioners, including midwives and traditional healers. In some of the more recent campaigns to eradicate the traditional custom, education remains a fundamental ingredient to the strategy.

There is abundant discussion about the success of the campaigns to eradicate FGC. For example, as it relates to trends, an examination of the data reveals that “the prevalence of female genital mutilation/cutting has reduced and on average the overall prevalence has fallen across generations” in some areas where the surgery is practiced.⁵⁷ The area where the decline is most significant is Kenya, a country where the focused area of eradication is most targeted.⁵⁸ Conversely, however the research demonstrates that in some countries there is an increase in the surgeries being done. In addition the surgeries where the increase is most prevalent, FGC is done by a health professional.⁵⁹ While some of the scholarship on the eradication of FGC shows a decrease in the practice, the data also reflects that FGC remains.⁶⁰

FGC is still practiced and some of the scholarship describes that practitioners have altered the way the procedure carried out. Scholars argue that the complete eradication of FGC is unlikely. One reason for the unlikelihood of the elimination of FGC, is that women of all socioeconomic and education levels are in favor of the traditional practice.⁶¹ Not only do women in FGC communities embrace the practice, the scholarship illustrates that FGC is typically controlled and managed by women. A second reason that the total elimination of FGC is doubtful is that the transmission of the practice is carried through the social norms, culture and customs, namely that of marriageability, a notion investigated in the chapter on Culture in this dissertation.

III. Globalization and FGC in the U.S.

One avenue for inspiring a more respectful and less ethnocentric discourse concerning FGC is to pay attention to the globalization of the U.S. The United States is rapidly becoming a more globalized society. According to estimates from the 2011 ACS, the U.S. immigrant population, those who now reside in the US, stood at almost 40.4 million, or 13 percent of the total U.S. population of 311.6 million.⁶² Such countries are characterized by diverse cultures that embrace very distinctive practices. One such practice is Female Genital Cutting (FGC). Worldwide approximately 80 to 140 million women have undergone FGC. It is estimated that 228,000 women in the U.S. have experienced FGC. As females and female refugees migrate from FGC communities to a non- female FGC reality, women bring their customs, beliefs, and values and they bring their health care needs.

Women from FGC/m communities, who live in the United States, face very distressing adjustments. An illustration of the adjustment is moving from a community where FGC is a social and cultural tradition, to living in an environment where the tradition is deemed taboo and even illegal for females under the age of eighteen to undergo. In all cultures there are concerns about being able to practice one's traditions, therefore being included in cultural traditions and customs are commonplace whether the tradition is characterized by males or females. Social norms and customs are complex, and to not address the complexities of social customs of those who migrate to the US from other countries has ethical implications. One implication is providing unbiased and non-discriminatory health care to people from different cultures and customs. Some of the scholarship on FGC articulates that in the U.S. there is unfamiliarity about the custom of FGC. Conversely however, genital modifications and particularly female circumcision in the U.S are not new. According to the history of FGC the practice was used in

the 1950's to cure female tendencies toward lesbianism, masturbation and behavior attributed to the hysteria of women.

With regard to the globalization of the U.S., the scholarship reflects that one area that globalization has dramatically effected is the image of women's bodies.⁶³ The globalization of these images has positively positioned female genital modification surgeries in North America. For example, in North America and Europe there is a popularized aesthetic ideal of a smooth and clean genital look.⁶⁴ This ideal has implications for the aesthetic reasons reported by women who embrace FGC in Africa. For example, "female genital surgeries in Africa are viewed by insiders as aesthetic enhancements of the body and are not to judged as mutilations"⁶⁵ a posture prevalent in the West. In addition, some genital surgeries, for instance labiaplasty done by cosmetic surgeons, is noted to be the "fasting growing form of cosmetic surgery in North America and Europe."⁶⁶ It is important to highlight that the scholarship describing labiaplasty, compares labiaplasty to that of Type I and Type II circumcision. A consequence of this kind of globalization is the need for inclusion of diverse cultural customs and traditions that may be controversial to the U.S. ethos. The globalization within the U.S. is not going away; neither will the integration of other cultural practices and traditions, namely FGC.

IV. Status

Female Genital Cutting (FGC) has moral importance. The moral important of FGC lies in the fact that the actors of FGC are "human properties."⁶⁷ In the investigation of moral status the notion of harm seems to be directly related to the idea of moral status, a theme associated with the health consequences of FGC. In addition, the scholarship on moral status notes "to cause pain is to cause harm."⁶⁸ The scholarship on moral status describes that actions that cause harm are morally unacceptable and taboo and that actions that cause harm are not permitted unless there is

a morally acceptable reason to justify the action that causes the harm, for instance the health consequences attributed to FGC. Scholars note about moral status, “experiencing pain and suffering are almost sufficiently to confer some measure of moral status.”⁶⁹

One of the main objectives of morality is to minimize pain and suffering. Included in the main objective is to prevent or limit indifference toward those who are experiencing pain and suffering. Women who experience the pain of FGC surgeries are intimately linked to the idea of preventing indifference. The notion of indifference mainly refers to the lack of concern and disinterest in the actor (women who have undergone FGC) so common found in the scholarship on FGC. Indifference therefore can be associated with the moral judgments made concerning FGC. Moral judgments however, “cannot be the end of the story; we must also decide what to do about our moral judgments”⁷⁰ and how the moral judgments made support the ethical care of women who have experienced FGC. Indifference is a view imbedded in the subject of FGC. The indifference is manifested in a number of ways. An illustration observed in the scholarship for example is that women who experience FGC are often discriminated against and shunned by the medical community in which they live. On the other hand, if women in FGC communities choose not to undergo the surgery they are rebuked by their community and indifference is created.

The lack of enthusiasm, concern and interest by both the healthcare community and their indigenous community is compelling. Additionally, it is curious that the main objective of determining moral status is to minimize pain. Could it be that the idea of harm reduction and autonomy as it relates to FGC is an act of morality and moral judgment that respects the cultural diversity and customs for those who are moral agents who desire to embrace their cultural tradition? A cultural tradition that is intimately connected to the identity of women who embrace

and undergo the surgery, a rationale for engaging in the practice and passing the cultural tradition on to future generations.

NOTES

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Chapter 2: Refugee Women, FGC, and Care

The current plight of refugees worldwide is compelling and complex. In 2007, the number of refugees globally stood at 11.4 million.¹ However by the end of 2010, the number of the “worlds refugees stood at 43.7 million.”² One of the complexities of refugees is being able to meet the needs and to provide assistance. Meeting the need of refugees and particularly refugee women is daunting.³ An equally challenging task is to meet the health care need of refugee women. Most problematic in meeting the need for care is that refugee women, suffer a host of physical problems that are often compounded by the immoral acts of violence, and dreadful persecution that they endure while on the journey to refuge which makes it difficult to provide care in settings that are without adequate facilities and expertise. Another complexity is refugees have been displaced from their homeland and the communities in which they lived. Refugee women will often migrate to places that may not respect or embrace different cultural traditions and customs to which they are accustomed, and invokes other health care needs. One factor under examination is what is owed to refugees. This chapter will give attention to constructing the notion of ‘refugees.’ In constructing the concept of refugees the question of who refugees are is addressed. Contextualizing refugee women in North American is the focus of section two. The section will consider refugee women who have experienced FGC. An exploration of the subject of human rights and its relation to refugees is included.⁴ The literature on refugees gives strong consideration of human rights when working with refugees. FGC and refugee women are a prominent feature in the literature on refugee women.⁵ Some of the scholarship regarding FGC, frames the practice as a violation of human rights, therefore an examination is warranted.⁶ FGC is criticized and condemned for the health consequences of the procedure, which impacts an already dismal health status of refugee women. For these reasons

the health status of refugee women is elaborated. One of the implications of refugee women migrating to new environments and integrating their cultural traditions and practices is that the customs are passed on to future generations. The concept of future generations is explored. Lastly, it is important to note that in the refugee discourse, the concept of refugee and displacement is often used interchangeably, and encompasses a host of factors also elaborated in this chapter.

I. Constructing the Concept of ‘Refugee’

One framework for constructing refugee status is the United Nations Human Rights Commission (UNHRC). The UNHRC defines a refugee as a person who has been “forced to flee his or her country because of persecution, war, or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. Most refugees cannot return home or are afraid to do so. There is fear due to war and the violence that is attributed to ethnic, religious and tribal conflicts. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries.”⁷ Individuals and groups who have been forced from their homes--having lost all ties to their communities, traditions, and customs, and forced to live in a countries and communities that are foreign to them. In many cases refugees are women. Women account for about half of any refugee, internally displaced or stateless population. Women refugees face a host of terrifying experiences and have endured the emotional, physical and perhaps spiritual consequences of being forced from home. With regard to refugees and how refugees are referred to, the scholarship on refugees uses several terms interchangeably that includes displacement, internal displacement, internal refugees, territorial displacement and forcibly displaced, terms used interchangeably by UNHRC. One scholar writing about refugees refers to the concept as “forced

eviction”⁸ to describe their status as refugees. The use of this term denotes that most often refugees are removed against their will and certainly without choice.

A. Types of Displacement

i. Internal Displacement

According to the Guiding Principles on Internal Displacement internally displaced persons (IDP’s) are defined as “individuals and groups who are forced or obliged to flee or to leave their homes or places of habitual residence, in particular as a result of, or in order to avoid the effects of armed conflict, situations of generalized violence, violation of human rights, or human-made disasters and who have crossed an internationally recognized state border.”⁹ The Guiding Principles on Internally Displaced Persons highlights two elements that are necessary and cannot be overlooked when identifying IDP’s. The first feature used to identify IDP’s is the movement against the will of the individual. In other words, “the coercive or otherwise involuntary character of movement-that is movement caused by armed conflict, violence, disaster, and the like and (2) the fact that such movements take place within national borders.”¹⁰ There is a second prerequisite that should be considered when identifying IDP’ and that according to the Guiding Principles on Internally Displaced Person should be acknowledged in a broader sense, particularly as it relates to where people who have been forced to flee their home find a shelter and safety. For example, an IDP must “first go abroad and then return to their own country but cannot go back to their home. Secondly, an IDP must voluntarily go to another part of the country in which they live, but cannot return to their place of origin.”¹¹ The criteria for being an IDP are also met if the individuals have to go through a state close by in order to access a safe part of their country of origin. The second criterion distinguishes IDP’s from refugees who are also involuntarily displaced but across internationally recognized state borders.

According to the scholarship an important difference between refugees and IDP's is the legal protection extended to refugees. Refugees have a universal and nonspecific protection under international law. However, there are no specific standards covering IDP's. As it relates to the UN, "no UN agency is specifically mandated to ensure their welfare."¹² The scholarship is clear about these differences. The major difference reflected describes that refugees have crossed international borders and are entitled to protection and assistance from the states into which they move and from the international community. Internal displacement occurs typically in response to armed conflict, persecution, situations of widespread violence, natural and human-made disasters and, more recently, large-scale development projects. However, both the scale of the problem and the nature of the response have become far more important in the last two decades. While the UNHRC has taken seriously the plight of IDP's, as evidenced by the Guiding Principles on Internal Displacement, scholars note that internally displaced persons do not have rights that are enforceable by "hard laws."¹³ The distinguishing factor that sets IDP's apart from refugees is that IDP's remain within the borders of a state where refugees have been forced across international borders. This characteristic is not to say that IDP's are not exposed to some of the same threats and dangerous situations that are experienced by refugees. On the contrary, IDP's are also vulnerable, at risk of harm and in need of protection.¹⁴

Internally displaced persons face horrific challenges. One specific challenge is that IDP's often flee their homes due to the threat that the government of the country in which they live is the source of their suffering and their displacement. In addition to the fear imposed by their government, IDP's face "deprivation and dangers associated with being driven from their homes."¹⁵ These dangers and the lack of protection and assistance offered by refugee and internal displacement agencies leaves IDPs unguarded, vulnerable and open to harm. The

implications of the idea that IDP's are without protection from laws that are unyielding and firm is ethically concerning, particularly as it relates to the care of women who are affected by FGC and in need of help. It is noteworthy to mention that IDPs have emerged as the largest group of people receiving UNHCR's protection and assistance.

At the beginning of 2011, there were as many as 14.7 million IDP's in 27 countries. Some of the literature on IDP's illustrates however that the total number of IDPs from conflict could be as high as 27.5 million. Due to the increase of IDP's the agency "has increasingly engaged with internally displaced people (IDPs), stateless people, populations affected by major natural disasters and people displaced in urban areas."¹⁶ Given the scholarship on refugees and IDP's and the controversy about how to call people who are displaced from their homeland, their communities, their livelihood, and traditions in which they are accustomed, both refugees and IDP's are in need of assistance and care.

ii. Forced Migration

The scholarship on forced migration illustrates that there is a host of debates and dilemmas, which are complicated when working with this population of people. One idea debated is the how to define the concept of forced migration. According to the literature, scholars agree that there is difficulty in producing a definition of "forced migration" that fully satisfies the interests, objectives and expectations of all involved, including forced migrants themselves."¹⁷

The International Association for the Study of Forced Migration (IASFM) describes forced migration as a term used in the general sense, and refers to the "movements of refugees and internally displaced people (those displaced by conflicts) as well as people displaced by natural or environmental disasters, chemical or nuclear disasters, famine, or development projects."¹⁸

The term forced migration implies the coerced movement of people away from their home or home region. It often denotes violent coercion, and is used interchangeably with the terms "displacement" or forced displacement.

Unlike most refugees, forced re-settlers (I refer here specifically to those displaced by infrastructural projects) have no choice about leaving their homes and cannot entertain the slightest hope of returning to them. Different from refugees, it is possible for the movement of IPD's to be planned well in advance. The authorities can therefore take steps to ensure that the disruptive impact of the move is minimized and that the standard of living of the re-settlers is improved, or at least maintained. It is important to conceptualize the notion of forced migration as it assists with interpretation and brings more deliberate attention to those who have no autonomous choice about leaving home and who are in need of care and assistance. In order to determine the connection to care, and the need to respond ethically as to determine what is morally best to do, examining this framework of forced migration is useful. Egide Rwamatwara writes that the concept of forced migration has "sometimes contradictory interpretations and connotations,"¹⁹ much like the idea of displaced persons and refugees mentioned earlier.

One example of the contradictory nature of interpretations used to describe the nuances and undertones of migration and forced migration is language. For instance, when describing forced migration verses, voluntary migration, the concepts are very different. When displacement is view from a place of contrast, forced migration is realized in the context of cause. On the other hand, when looking at displacement from the viewpoint of voluntary migration, a purpose for electing to migrate is understood. In this way displacement is viewed from a cause and purpose lens.²⁰ In other words, for some there are causes associated with forced migration while others migrate voluntarily for a specific purpose. From this viewpoint, forced migration as it were, has

root causes where voluntary migration is embedded in purpose. Using the framework of cause and purpose, migration can be referred to as migration that is tied to trade, industry, and financial viability, as opposed to migration that involve a combination of social and political factors. Clearly, one form of migration describes migrants (emphasizing purpose) who leave their homes to go elsewhere in search of the opportunity for a better life facilitated by employment, business or education.²¹ On the other hand, (emphasizing cause) migrants flee from their homes and place of residence because they must protect themselves and their families from the immediate threat of harm. These are different variables that lead to migration.

As it relates to language, other scholars use the terms “proactive and reactive” migration. Some writings about migration classify migrants in two main categories, those with agency or choice (autonomy) and those without agency. For example, those without agency are “forced migrants with little to no agency”²² who are forced to leave their country against their will. With regard to the bioethics scholarship the notion of agency is important and is investigated in chapter three of this dissertation. Agency is linked to the right to self- determination which when taken away leaves people and groups of people vulnerable. The state of vulnerability has implications for providing care and assistance for those in need.²³

According to the UNHCR’s demographic data on forced displacement approximately “33.9 million people were ‘people of concern’ to UNHCR at the start of 2011, an increase from 19.2 million in 2005.”²⁴ While the increase is inclusive of both men and women, the trend reflected in the scholarship is that there is an increase in the number of refugees who are women. For example, the forced migration research emphasizes that “one of the most significant trends in migration has been the entry of women into migration streams that once had been primarily male.”²⁵ The literature further illustrates that approximately half of the migrants globally are

women. This particular trend is critical to supporting the focus on women who migrate to western countries, namely the US. As women migrate from other culturally diverse communities they bring their cultural customs, beliefs, traditions, values and practices with them and look to integrate them into the place where they have settled. One example of the integration of a cultural custom is FGC.

iii. Asylum Designation

Another component of the refugee discourse is the legal designation of asylum. Not only is it of foremost consideration in the legal discourse concerning refugees and FGC, but the literature shows that FGC has been used as grounds for asylum in other countries and specifically the United States. Asylum is defined as the protection granted by a nation to someone who has left his or her native country as a political refugee. The International Spectrum at the University of Michigan defines asylum in a more specific sense, and notes that asylum is “a form of protection extended to individuals by the U.S. government.”²⁶ It is important to note that a person must be designated as refugee in order to seek asylum. Distinctive to the idea of asylum is that those who seek the asylum must be able to prove that they are in imminent danger and that there is well founded fear of persecution. The persecution must be based on race, religion, nationality, membership in a particular social group, or political opinion. Specifically, the persecution must be imposed by the government or a group the government cannot control. A person who is granted political asylum may remain in the U.S. indefinitely and may apply for permanent residence after one year.

According to estimates from the United Nations High Commissioner for Refugees (UNHCR), since 1998 the United States has processed an average of 46,000 asylum applications each year. Winning asylum in this country, however, is not an easy task. On average, only 62

percent of applications have been successful. While the idea of asylum has traditionally focused on fear of persecution due to one's religion, race or political association, in recent years Female Genital Cutting has been used as grounds for asylum. There is a plethora of scholarship, namely legal scholarship as it relates to claims for asylum.²⁷ The 1996 landmark case; *In Re Fauziya Kasinga* is a case that is frequently mentioned regarding asylum and FGC. Fauziya Kasinga is a Togolese woman who was awarded political asylum in the United States by the Immigration and Naturalization Service in order to escape having the genital cutting procedure.²⁸

In so far as the literature illustrates, being granting asylum in the United States due to FGC is very difficult for a refugee or immigrant women to attain. Further, the U.S. has been "reluctant to recognize FGM as grounds for granting asylum."²⁹ It is not that the U.S. has not adopted the doctrine outlined in 1967 Protocol, and the 1951 United Nations Convention Related to Status of Refugees, the challenge is determining what constitutes persecution. It is important to note that the Refugee Act gives authority to governments to grant asylum, but the person requesting must meet the definition of refugee. While the Refugee Act gives this authority to the government, a women seeking asylum in the US must demonstrate four factors that include fear and well founded fear of persecution that the government or official of the government in which she lives will inflict persecution. While fear of persecution must be demonstrated before asylum is awarded, the scholarship on asylum and FGC describes that fear of persecution is most often difficult to prove. What is equally difficult in linking FGC to asylum is that the traditional custom is often referred to as a gender based act of violence. Gender-violence based claims "do not fit easily into the statutory definition of refugee because gender is not one of the enumerated grounds to define refugee status."³⁰

The consideration to determine FGC persecution and to grant asylum on the bases of it is challenging at best. Much of the literature on asylum and FGC also include the human rights discourse which at times is used to further the case for asylum when linking the custom as a violation of human rights. Although the viewpoint of the UNHCR is that the violation of human rights has the potential to constitute persecution,³¹ other statutes and legislative bodies of work regarding refugee and asylum law are cautious. For example, some of the immigration literature discloses that the immigration statutes “do not define the term and thus the courts are faced with the challenge of determining whether FGC should be considered a human rights violation thus persecution.”³² The literature further describes that in its purest state, FGC is not a form of punishment or persecution rather it is primarily an ancient custom.

iv. Refugee

One of the major themes in the scholarship on refugees is what the term “refugee” means. While the UNCHR gives definition for the term, the literature shows that the term ‘refugee’ is weighty at best. It holds a plethora of nuances and distinction across disciplines. One scholar writes that the term refugee, carries not only empirical sociological and socio-political connotation but above all, is a normative and a legal category enshrined as such in international law.”³³ With regard to international law, Morawa affirms the conclusiveness of this statement citing the Convention of Belem do Para. The Convention reads, “state parties shall take special account for migrants, refugees or displaced people, who are vulnerable due to their “liberty status”³⁴ a status that deprives them of their liberty.

Concerning the concept of refugee, and its meaning, some scholars embrace the idea that the “territorially displaced person is a category that includes refugees, the internally displaced

and forced migration.”³⁵ Other scholars use the word displacement interchangeably to refer to refugees. The UNHRC uses the concept of “forcibly displaced”³⁶ to refer to refugees. A further exploration of the literature shows that within the rubric of territorial displacement, there is a marked distinction between the concept of internally displaced persons (IDPs) and refugees. Earlier in this chapter an IPD is defined as a person who has been forced to flee his or her home for the same reason as a refugee, but remains in his or her own country and has not crossed an international border. Unlike refugees, IDPs are not protected by international law or eligible to receive various types of aid.

The United Nations Human Rights Commission (UNHRC) defines a refugee as “someone who has been forced to flee his or her country because of persecution, war, violence, or a well-founded fear of persecution for reasons of race, religion, nationality, political opinion, or membership in a particular social group.”³⁷ A feature in what is included in determining refugee status is that refugees cannot return home. Not being able to return home is most likely due to fear of war, religious, ethnic and tribal violence, which are also the leading causes of what forces refugees to leave their country. There is an extraordinary and unparalleled number of refugees fleeing persecution. As of June 20, 2011, “war and political repression were responsible for 43.7 million people being displaced from their homes by the end of 2010.”³⁸ The literature further shows that the highest number of refugee populations is found in Pakistan, and the Democratic Republic of Congo. Related to where refugees find refuge the UNHCR reports that it is the world’s poorest countries that have little or no resources that are hosting refugees and displaced peoples. Further, “27.5 million people are displaced in their own country with the pervasive indicator for the displacement being conflict and there are nearly 850,000 asylum seekers one fifth of them in South Africa alone”³⁹

Since the traditional and cultural practice of FGC is extensive in Africa, it is prudent to mention the African context as it relates to refugee women. What is interesting in the context of Africa, specifically the Great Lake Region (GLR) is that the statistics on forced displacement reveal that the vast majority of displaced persons found in the GLR originated from that very region. The countries include Burundi, Democratic Republic of Congo (DRC), Kenya, Rwanda, Tanzania and Uganda. The GLR “are the six core countries of the Great Lakes Region of Africa and are called the GLR because the countries are located around Lakes Victoria, Tanganyika, Albert, and Kivu”⁴⁰ The GLR is important to highlight as no other region on the African continent “has a forced displacement problem of comparable duration or magnitude.”⁴¹ The GLR is a region that is beleaguered by relentless violence. It is also noteworthy that Kenya is one of the countries where FGC is most prevalent.

As the nature of war has changed in the last few decades, and the onset of more internal conflicts replacing wars among countries, the number of IDPs has increased significantly.”⁴² Both refugees and IDPs have been mandated to leave the place where they once lived. While there are similarities in the experiences of refugees and IDPs, Bushra, and Fish explain, there are considerable differences.⁴³ They write, “refugees have crossed international borders and are entitled to protection and assistance from the states into which they move and from the international community, which is facilitated through the United Nations (UN) and its specialist agencies.”⁴⁴ In other words, refugees are protected under the international law and IDP’s are not.

B. The Legal Guidelines for Determining Refugee Status

In its legal sense the term refugee represents protection that may be granted to individuals who meet the definition of ‘refugee.’ Refugees are generally people outside of their country who are unable or unwilling to return home because they fear serious abuse and loss of life. The term

refugee is a legal term and implies a legal status. Formally, under United States law, according to the U.S. Citizenship and Immigration Services, the guidelines for determining refugee status apply to someone who is located outside of the United States, is of special humanitarian concern to the U.S., demonstrates that he or she is persecuted or fears persecution due to race, religion, nationality, political opinion, or membership in a particular social group and is not firmly resettled in another country and is admissible to the United States.⁴⁵ Since the dissertation distinctly explores women who are refugees it is noteworthy that women make up approximately half of the world's refugee population.

According to the UNCHR, refugees often live in overcrowded camps. Due to this overcrowded environment women are especially vulnerable to atrocities related to sexual violence.⁴⁶ These forms of cruelty and aggression include “rape, forced impregnation, forced abortion, sexual slavery, and the intentional spread of sexually transmitted infections, including HIV/AIDS. The transmittal of HIV/AIDS is one of the defining characteristics of contemporary armed conflict. Its primary targets are women and girls.”⁴⁷ These acts of sexual violence are described in the scholarship as gendered based violence and warrant the need for protection. It is important to note here that external threats also include other forms of infectious diseases found in environments of extreme poverty, namely refugee camps. In addition to HIV/AIDS infections, other infectious diseases include, malaria, tuberculosis. Women and girls who suffer these highlighted external threats are powerless and do not have the ability to protect themselves or their self interest, therefore protection is needed for the survival of those who are unable and powerlessness of protecting their interests as they have inadequate means to do so,⁴⁸ and are in need of assistance. Therefore the legal status of refugee is critical.

Refugees, particularly women who have insufficient means are not only susceptible to external threats, for example the oppressive governing social order, but they are open to internal threats as well. External threats are vulnerabilities that threaten one's opportunity to participate in the mainstream of life. One example of an external threat that impedes the ability for refugee women to participate in life in a holistic way is not having "equal access to food, water, and non-food items, and are a fundamental issue facing refugee and displaced women and their children."⁴⁹ An opportunity to participate in the mainstream of life rather than on the margins must be afforded refugee women. Seemingly, to provide refugee women with access to assistance and support is what morality recommends. The global bioethics discourse advances not only the idea of external threats mentioned earlier but also internal threats. Internal threats are those internal factors that influence the genetic disposition of individuals who live in poverty for instance refugees, namely women, to be able to fight malaria, tuberculosis, and HIV infection.⁵⁰ The authors further explain, "internal factors such as age, sex, and genetics can influence a biological response to malaria, tuberculosis, and HIV infection."⁵¹ A global bioethical viewpoint on refugees and what refugees are owed is situated in a holistic context, which includes the individuals but also recognizes that the individual is part of wider community. It is here that the status of refugee granted as a legal status determines that the refugee is owed assistance as articulated by UNHCR.

i. International documents

In July 1951, a conference in Geneva developed and adopted the *Convention relating to the Status of Refugees* ('1951 Convention'). The 1951 Convention was later amended by the 1967 Protocol. The Convention relating to the status of Refugees is the underpinning and the foundation for international refugee law. The legal documents provide a framework and

guidelines for determining who a refugee is. The document also highlights the legal protection and social rights entitled to refugees, as well as other assistance including the need for care.⁵² Not only does the 1951 Convention and the 1967 Protocol make clear what is owed to refugees, it also defines the obligatory relationship that refugees have to host countries and identifies specific categories of people, such as criminals, particularly those who were involved in war crimes and others who do not qualify for refugee status. The idea of what is owed to refugees is central to the refugee scholarship. As it relates to the focus on what refugees are entitled too, according to the provision in the 1951 Convention and its 1967 Protocol, “refugees deserve, as a minimum, the same standards of treatment enjoyed by other foreign nationals in a given country and, in many cases, the same treatment as nationals.”⁵³ In other words, on the authority of the 1951 Convention and the 1967 Protocol refugees who reside in the U.S. for example, are at a minimum due the same benefits and provisions enjoyed by individuals who are citizens of the United States. Some of these benefits and provisions include, access to food, shelter, clothing and medical care. Certainly one provision enjoyed by individuals who are nationals in any country is the benefit of protection.

Protection is a substantive theme in the scholarship on refugees and is a benefit of overwhelming concern to refugees and those who care for refugees. Refugees are vulnerable to a number of efforts that are intended to promote harm. While all refugees are open to potential harm and abuses that includes human rights violations, and various forms of violence, women remain particularly vulnerable. Women share the vulnerabilities that are experienced by all refugees however, women and girls have “special protection needs that reflect their gender.”⁵⁴ Gender specific need for protection consists of protection from sexual and physical abuse, exploitation that leads to human trafficking, and protection from gender discrimination which

makes gender a barrier to accessing goods and services. One theme that is central to gender specific protection is FGC which is described as violence against women and a violation of human rights.⁵⁵ It is important to mention that a significant amount of the FGC scholarship describes the traditional culture custom as a form of gender violence against women.

A second international document, and one of the most prominent, is the UNHCR *Guidelines on the Protection of Refugee Women (GPRW)*. These guidelines follow the general framework outlined in the UNHCR Policy on Refugee Women. The main aim of the policy is to “integrate the resources needs of refugee women into all aspects of programming and to ensure equitable protection and assistance.”⁵⁶ The GPRW establishes with certainty that refugee women face dangerous situations that are at times life threatening. The risks are enormous. The enormity and gravity of the situations present particular challenges related to protection. For example, women are often violently attacked, raped and kidnapped. Therefore it is the physical security that is needed to protect refugee women. The GPRW allows for collaborative efforts to provide interventions when the need arises. In addition, the Guidelines on the Protection of Refugee Women provide a legal framework for protection of refugee women.

The *Canadian Guidelines* is another resource in the international scholarship on refugees that assist in providing guidance and help for refugees is Canada’s Immigration and Refugee Board (IRB). The IRB issued these guidelines that are entitled the “Women’s Claimant Fearing Gender Related Persecution,”⁵⁷ now known as the *Canadian Guidelines*. The aim of these guidelines is to provide the IRB who make decisions concerning refugees with an avenue for interpreting the legal definition of a refugee that pays attention to the issue of gender thereby making decisions with sensitivity toward the challenges of women. The source of inspiration for the Canadian Guidelines is due to the plight of refugee women made “unsuccessful claims based

on gender related persecution.”⁵⁸ Those who are seeking refuge into Canada must first comply with the Convention criteria to be deemed a refugee.

In Canada however, the country is concerned with how those coming into the nation state will be able to settle in the country. For instance, the government employs a criterion of “personal suitability or admissibility.”⁵⁹ In other words the country evaluates how well those coming to Canada will be able to assimilate in terms of education, level of employment skill and how well they speak the languages that are used in Canada. Gender is not mentioned in the suitability. However the discussion on refugees in Canada is important as the scholarship on refugees illustrates that there is a sizable African refugee population in Canada. Certainly employing both the UNHCR, Guidelines on the Protection of Refugee Women and the Canadian Guideline will assist and give guidance on what is owed to refugee women, as these documents provide a general framework for determining refugees the status of refugee.

ii. U.S. Documents

According to the United States Immigration and Nationality Act (INA) and Under United States law, a refugee is someone who is located outside of the United States, is of special humanitarian concern to the United States, and demonstrates that they were persecuted. The persecution must be attributed to the person seeking refugee status. Also the fear of persecution due to race, religion, nationality, political opinion, or membership in a particular social group is key. Lastly, the person seeking refugee status can not be firmly resettled in another country and is admissible to the United States. In other words, refugee status may be granted to people as a form of protection who meet the definition of refugee as articulated by (UNHCR) and who are of special humanitarian concern to the US. These individuals have been persecuted or fear they will be persecuted because of their race, religious preference, nationality, and/or membership in a

particular social or political group. What is interesting is that the US law concerning refugee status uses the language that the person or persons must “demonstrate” that they were or are in fear of persecution.

iii. UNHCR

The United Nations High Commission on Refugees is the leading agency on the subject of refugees and offers a wealth of information and guidelines as it relates to refugees. Much of the efforts worldwide concerning refugees have been inspired by the UNHCR. The UNHCR is the only global legal bodies explicitly covering the most important aspects of a refugee’s life. The Office of the United Nations High Commissioner for Refugees (UNHCR), established in 1950 by the United Nations General Assembly was developed to lead and coordinate international efforts and action to protect refugees and to find solutions to problems that are specific to refugees. The primary purpose of UNHCR is to safeguard the rights and well-being of refugees and to find answers to problems facing refugees globally. It strives to ensure that everyone can exercise the right to seek asylum, find safe passage and refuge in another state while protecting the option of refugees to return home voluntarily if they choose. The office is entrusted with the work of integrating refugees locally or to provide assistance for resettling in a third country. One major focus of the UNHCR is the protection of refugees. This center of interest and activity for the agency is illustrated in the definition of who refugees are. For example, one classification described in the UNCHR is the idea of persecution and more specifically gender violence and persecution.

While the UNHCR has special interest in the protection of all refugees, the agency has a particular interest toward women and their children. To be sure, there is a UNHCR Policy on Refugee Women. The Policy intentionally contains four general conclusions that relate

specifically to refugee women. For example, the policy describes that in 1985 the Executive Committee adopted what is called conclusion No. 39 entitled, Refugee Women and International Protection, noting that “refugee women have protection and assistance needs which necessitate special attention in order to improve existing protection and assistance.”⁶⁰ The UNHCR encouraged all programs, states and concerned agencies to support its efforts. In 1987, 1988, and 1989 consecutively, items were added to the policy that included international protection, further elaboration on the extraordinary vulnerability of women, the distinct problems of physical security, and sexual exploration. In the description of what constitutes the legal definition of a refugee, the UNHCR describes that one stipulation is that there is a well founded fear of persecution. In the UNHCR literature one of the treatment claims related to persecution is that of FGC-(M). The notes explains, “that a women or girl seeking asylum because she has been compelled to undergo, or is likely to be subject to FGM, can qualify for refugee status.”⁶¹ As it relates to contextualizing refugees the scholarship, including the UNHCR literature connects refugee women to FGC.

II. Contextualizing Refugees

A. Distinct Groups of Refugee Women

In an effort to contextualize refugee women, and for the purposes of this dissertation, the connection between refugee women and FGC is critical. The scholarship on both refugee women and on FGC agrees that North America has become more globalized and is populated with immigrants and refugees who bring their desire to integrate their cultural practices with them.⁶² With this influx of people from other countries settling in the US, the characteristics and the cultural practices of the migrating populations are important to give attention too. According to the Center for Disease Control (CDC), in 1999 the agency estimated that there are over 168,000

women and girls who reported that their place of origin was from a country that practiced female circumcision. One scholar articulates the growth of people from female genital cutting countries and communities observing that “there is an influx of refugee and immigrant populations from African societies, many of whom practice genital cutting.”⁶³ This observation gives way to identifying one distinct group of women living in the US, women who have involuntarily experienced FGC.

i. Refugee Women Experiencing FGC Involuntarily.

Women who involuntarily experience FGC is one of the leading themes of the scholarship on FGC and on refugee women. Involuntary FGC is characterized as one form of gender-based violence. The UNHCR considers “FGM to be a form of gender-based violence.”⁶⁴ In addition, the FGC literature describes FGM not only as a violent act against women it is characterized as a form of persecution, especially in human rights law.⁶⁵ The UNHCR deems all forms and types of FGC a violation of the human rights of women and girls. Furthermore, FGC is established by the UNHCR as a well-founded fear of persecution for both women and their daughters. The literature reflects that there is both the fear of being forced to undergo the procedure and the fear of facing persecution for refusing to force their daughters to have the surgery. Because sexually based gender violence can occur at any time during the stages of the refugee cycle, the idea of “human security raises the awareness of threats against the physical security of refugee women.”⁶⁶ As discussed earlier in this dissertation the need for protection for women being forced to undergo FGC is of deep concern. Due to the host of medical issues women face as a result of the way that FGC is often performed, the need for adequate health care and access to care is critical. It is here that refugee women experiencing involuntary FGC who migrate and resettle in non FGC communities are a distinct group of women who need care.

ii. Refugee Women Who Voluntarily Choose FGC

In contrast to the women who involuntarily undergo FGC, a distinctly different group of women becomes clear. This group of refugee women is women who have migrated from FGC communities who choose and will voluntarily undergo the procedure. A dilemma for these particular women is how to continue to practice the rituals of their culture outside of their native geographical context. To abandon these cultural traditions is not something that women choose to do, and the obligation to practice cultural customs outside their indigenous country is quite persuasive. Another predicament for women that resettle in an environment where FGC is not practiced is that the custom at times can be against the law, there is an unfamiliarity with the custom and there are strategies to eradicate FGC underway. These kinds of situations make it probable that attempts to practice FGC/c underground are likely to occur; contributing to the danger and harmfulness of the practice as well as the need for care. It is here that the analysis of care must include cultural competency, explained in chapter six. Many immigrants and refugee families have established very strong support systems that reflect their social, religious, and ethnic practices to which they have strong ties. The idea that there are women who will choose to voluntarily undergo FGC is not a theme in the FGC scholarship nor is it given able consideration. Nevertheless, there are women who will not abandon the practice and will choose to undergo the procedure. FGC is a cultural custom that is associated with diverse reasons and rationales and is not going away.

The reasons for the custom vary depending upon ethnic groups and not every ethnic group shares meanings and motives for the practice, however the reasons and rationales are linked to voluntary choice. One reason for voluntary choice that is not articulated in a transparent way is the idea of body image or aesthetics. Aesthetics is mentioned but rarely given

focused consideration. In an investigation of the more balanced scholarship for example, women embrace and choose FGC, especially in Africa for reasons of body image. Body image is an idea that is commonplace in the US. The idea of body beautification and improvement, is a universal ideal and “many women who have had gentile surgery view the procedure as a cosmetic beautification, moral enhancement or dignifying improvement of the appearance of the human body.”⁶⁷ The notion of cosmetic enhancement is not an uncommon rationale for FGC, and it is a reason for all types of body image surgery.

One scholar argues, as it relates to aesthetics that, “gender identity is also a frequently significant feature of genital surgery from the viewpoint of insiders who support the practice.”⁶⁸ Through the exploration of the scholarship we have established that there are a host of reasons, meanings, values and features of this cultural tradition. Being able to bring their customs and maintain traditional practices unearths the practical need that necessitates paying attention to this group of women who support the practice and will choose to undergo the surgery. While the idea of body image is not one of the features of this dissertation the notion is relevant to the investigation of FGC and deserves further exploration.

B. Human Rights and Refugees

Relevant and absolutely crucial to the refugee and FGC discourse is the notion of Human Rights. As it relates to refugee women and FGC, the idea of human rights is examined via International Human Rights Law (IHRL) as it is this framework that regards FGC as a human rights violation of women. It is interesting to note however that the scholarship on human rights describes that while the term human rights is often used, it is not been “authoritatively defined.”⁶⁹ The human rights framework includes moral and political claims that all human beings have a right to expect from government as a right, rather than as a act of kindness which

can be revoked at any time. As it relates to the scholarship on FGC and human rights, the literature illustrates that the human rights of women who involuntarily undergo the procedure are compromised by FGC.

In order to highlight some of the rights that scholars argue FGC violates, it is helpful to very briefly mention the progression of the evolution of human rights as other scholars writing about human rights argue that international human rights law does not give governments the authority to interfere with the practice of FGC.⁷⁰ In the eighteenth century a body of rights emerged that are often referred to as “first generation rights.”⁷¹ These rights include freedom of opinion, conscience and religion, the right to freedom of association and the right to own property. In the late nineteenth and early twentieth century a “second generation”⁷² of rights materialized that focused on economics, social and cultural rights and included that persons have the right to social security, education, and health. Finally, a “third generation”⁷³ of rights pays particular attention to the environment, peace, and humanitarian assistance.

An equally impactful component in the body of literature on human rights particularly as it relates to refugee women and FGC is the various sources of International Human Rights Law. These sources are significant as they represent the treaties that are enacted by international human rights law. These treaties and laws provide the context in which particular groups of people especially women are addressed. One of the most reliable and authoritative documents are the Universal Declaration treaties at both the international and regional level. The UN Declaration of Human Rights “is one of the most influential legal and political instruments of the twentieth century.”⁷⁴ The International Covenant on Civil and Political Rights and the International Covenant on Economic and Social Rights is also included.

According to Rahman and Toubia, legal action against FGC is found in more recent treaties, specifically in the 1979 Women's Convention and the 1980 Children's Rights Convention.⁷⁵ Since it is these two treaties that focus on the rights of both women and children, these treaties are often used as a strategy to advocate from a humans rights perspective for abolishment of FGC.⁷⁶ It is critical to mention that these treaties do not specifically mention FGC rather they promote values embraced by both domestic and international communities against the practice. There are also regional treaties that place obligatory constraints, for example the African Charter on Human and People Rights, the European Convention for the Protection of Human Rights and Fundamental Freedoms and the American Convention on Human Rights. All of the treaties and conventions mentioned above have at their core, the right to life, liberty/freedom, and security.

As it relates to application the human rights scholarship interprets the practice FGC/M as "infringement on certain rights."⁷⁷ These rights include freedom from all forms of discrimination, violence and right to life, dignity and physical integrity. For the purposes of this dissertation it is important to mention that there are also other international human rights raised by FGC, namely, cultural rights or a right to culture; these will be more fully investigated in the chapter on Culture Diversity. However, it is the idea of culture and physical integrity that those who embrace the practice argue for a balanced evaluation of the cultural practice. For example, while the human rights scholarship regards FGC as a form of violation of physical integrity of women who undergo the practice, other scholars writing about human rights and FGC note that adult women should be free to choose what makes them happy with their own bodies.⁷⁸

In the United States the human rights of all people are legally protected by the Constitution of the United States and amendments, conferred by treaty, and enacted legislatively

through Congress, state and legislatures. The literature on human rights in the West reveals that “the protection of fundamental human rights was foundational to the establishment of the United States.”⁷⁹ Since that time, “a central goal of U.S. foreign policy has been the promotion of respect for human rights, as embodied in the *Universal Declaration of Human Rights*. ”⁸⁰ Human rights, as interpreted helps secure peace, deter aggression, promote the rule of law, combat crime and corruption, strengthen democracies, and prevent humanitarian crises. However, an important observation of the western view point of human rights is its notable focus on individuality and economics.

Concerning the centrality of the individualistic and economic framework of the west, one scholar describes, “that economic, social and cultural rights do not have the priority that some commentators (in Africa) feel they deserve and is frequently attributed to the alleged bias in philosophical thought about rights in the west.”⁸¹ The lack of integration concerning social and cultural rights (as markets are the major construct) is an important observation when examining human rights construct in the West, particularly as women refugees migrate to the US and who voluntarily choose to undergo FGC. The significance of the human rights construct in the West is found in the reality that people from other cultures settle in the US therefore an emphasis on cultural rights and communal focus rather than an individualist one is needed. In fact, Hollenbach writes that “indeed during the Bush administration era, there was even stronger conviction that markets by themselves are key to development.”⁸² This is not to say that these concepts are not important to human rights conceptualization in Africa. Nevertheless, the economic individualistic tenor of western human rights must integrate cultural rights and a communal focus which creates a more balanced framework so that human rights is for “everyone, everywhere, for men and women, for children and the elderly, for people of different

cultures, tribes and backgrounds.”⁸³ In doing so the promotion of human rights is realized in the US framework.

C. Health Status of Refugees

According to the Refugee Health Organization in 2010 the U.S. accepted more than 73,000 new refugee arrivals. Forty seven percent (47.3%) of these new arrivals to the U.S. were refugee women. Female refugees represent a vulnerable group who are often survivors of human rights abuses, and need special attention and care. The experiences of migration whether it is voluntary or involuntary can have profound consequence for the health of refugee women. Further, there are specific health complications that are experienced by refugee women, for example infectious disease and reproductive health issues.⁸⁴ To be sure, the research makes clear that refugee women are “dealing with special problems such as ritual female genital surgery.”⁸⁵ In highlighting some of the health consequences of FGC as a health issue that presents special problems, concerns are raised in connection to access to health care that includes an acceptable level of reproductive care.⁸⁶ The refugee scholarship describes that the major problem as it relates to the health status of refugee women is that refugee women are more likely to experience delays in accessing health services and face disparities in reproductive health outcomes.⁸⁷

Therefore the UNHCR literature make clear that refugees have a right to basic medical care and have made efforts to support care for refugees a major priority. In addition to basic medical care, the UNHCR has deemed reproductive health as a right. The agency defines reproductive health as s state of “complete physical, mental and social well being and not merely the absence of disease and infirmity, in all matters relating to the reproductive system and to its functions and process.”⁸⁸ Some of the priorities as it relates to reproductive health are childbirth, unsafe abortions and post abortion care and FGC. While health complications related to FGC are

fully elaborated in chapter one, it is important here to make the specific connection between reproductive health, FGC and refugee women.

Refugee women not only suffer from reproductive health complications they experience other significant health effects that are physical, mental and emotional. Some of the scholarship reveals however that the health problems refugee women experience are not very different than those women who live in developing countries.⁸⁹ One of the similarities, for example is coping with life threatening disease. These life threatening diseases include, but are not limited to malaria, measles, tuberculosis, and HIV infection. Other commonalities experienced by refugee women and women in developing countries are complications related to childbearing, psychiatric disorders and problems from the trauma of displacement. The dangerous journey refugee women face however complicates the health problems they experience.

Health risks and complications of reproductive health are critical when exploring health related concerns of refugee women. The reproductive health concern related to pregnancy is important to mention. Pregnancy and giving birth are reflected in the FGC scholarship as a health concern for refugee women who have experienced the procedure and remain circumcised upon delivery. Deaths related to obstetric complications are among the primary reason for death of refugee women and girls. As it relates to FGC it is women who have experienced Type III infibulation who are at risk of obstructed labor resulting in fetal death and further physical complications for the mother. Other concerns related to reproductive health that are associated with FGC are infertility. The scholarship suggests that the infertility is due to infections caused by the use unsanitary instruments. Important to the examination of reproductive health, namely FGC, is what the scholarship regards as insufficient and inadequate health care, not only to care

for women who are suffering from reproductive health concerns in general, but FGC specifically. When working with the complexities of the health status of refugee women, health interventions that support reproductive health care are critical.⁹⁰ A health intervention on the unmet needs of refugee women can be met by adequate training of health care providers to provide a level of care that is sufficient for women who need help now and for future generations to come.

D. Future Generations

The concept of future generations is a bioethical concept in the UNESCO Universal Declarations on Bioethics and Human Rights. The idea of “Protecting Future Generations” is one of thirty articles set forth by the Declaration. In its most basic form the article means that all bioethical issues should be examined for the benefit of both present and future generations.⁹¹ The article is intimately linked with another document adopted by UNESCO: the Declaration on the Responsibilities of the Present Generations towards Future Generations. The impetus for the article comes from the examination of the relationship between both present and future generations, the environment, and the life sciences. It asks the question; what is the moral responsibility of this present generation for future generations. The work of the present has implications on the future, particularly when the implications affect humankind. Humanity here, notes one scholar, is not only “the international community, including all people living today, but it refers to the chain of generations who will collectively form one community whether living now or in the future.”⁹² This implies that all decisions made particularly as it relates to bioethics should consider the impact of the decision on future generations.

The Declaration on the Responsibilities of the Present Generations towards Future Generations is considered a legal instrument. This declaration offers twelve articles. While all of the articles are important, some articles are more closely related to the discussion of present

generations of women who have experienced FGC, and future generations who will choose to undergo the surgery.⁹³ These articles include article two, (2) freedom of choice, article seven, (7) cultural diversity, and article eleven, (11) non-discrimination. It is important to mention that both article two (2) and article seven (7) are part of the western and global bioethical framework and are investigated later in this dissertation. Therefore, the application of the articles to refugee women experiencing FGC serve as themes that assist in providing an ongoing ethical analysis of care for these distinct group of women now and in the future.

The Declaration reflects concern for the destiny of future generations. It further states that the fate of generations to come is incumbent upon the decisions and actions employed today and that any issue must be resolved in a manner in which future generations are considered. The declaration also asserts, “there is a moral obligation to formulate behavioral guidelines for the present generations within a broad, future oriented perspective.”⁹⁴ In other words, there is a moral imperative of the present generation to ensure that not only the ecological community is safeguarded, but also to make certain that human rights and interests and the bioethical principles that guide behavior of the human community are not jeopardized. An example of not jeopardizing human rights is the idea illuminated in the Declaration concerning future generations regarding non-discrimination. Some of the scholarship on FGC argues that not only is FGC a violation of human rights but the practice is also discriminatory in nature.

Conversely however, other scholars, writing about the traditional practice argue that it is not discriminatory as both male and females experience circumcision.⁹⁵ Nevertheless, what may be regarded as discriminatory is to take action (eradication) preventing freedom of choice, namely being able to choose to undergo FGC. To eliminate the practice could be interpreted or viewed as discriminatory in that eradication takes away the freedom to choose or self-

determination. Taking away the ability to honor a women's cultural heritage and the practices thereof for women in this present generation, and certainly in future generations is discriminatory. To not apply the non-discrimination article for example to refugee women, FGC, and future generations, interferes with the right to education that informs women in future generations that the practice in the past had been administered in ways that are harmful (through no fault of their own). Yet, in looking to the present generation and more importantly to future generations, decisions that are made presently concerning FGC could effect how the surgery can be practiced in the future, namely, in ways that are medically appropriate and that reduce harm.

III. CONCLUSION

The refugee population once dominated by males is now made up of approximately half women.⁹⁶ Many of the female refugees are from FGC communities and have experienced FGC. The health related consequences related to the procedure are at the core of the objections concerning the traditional practice. Refugee women who have undergone the surgery are in need of health care To not provide care is unethical, and to provide sub-standard health care is unacceptable. While the current status of women experiencing FGC is one where the procedure has been done involuntarily, migrating too, and making a life in a non FGC environment lends itself to women having choice and voluntarily undergoing the procedure. Since FGC is a custom that is embraced by some women, particularly in Africa,⁹⁷ it is reasonable to determine that refugees who migrate to non FGC communities will look for ways to integrate their cultural rituals into their current context. One implication of refugee women integrating traditional practices into a new life context is the influence on future generations. Future generations are one way to transmit cultural ideals, beliefs and customs.⁹⁸ Therefore, while some of the present

generation advocates for the eradication of FGC, it is ethically important to safeguard both the present and future generations right to self-determination and autonomous choice.

NOTES

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Chapter 3: Respect for Autonomy, Women Refugees and Care

This chapter explains the rationale for considering respect for autonomy in this dissertation.¹ The respect for autonomy concept provides a valuable and effective construct with which moral dilemmas can be analyzed.² Applying this construct compels us to use a specific lens in making distinctions in the groups of women under question. The lens allows for a particular demarcation between women who have undergone the intervention voluntarily or involuntarily. The last option is ethically not acceptable. But the first one requires ethical analysis and reflection, weighing the free choice of the women, respect for cultural diversity, and non-maleficence. A second reason to consider respect for autonomy in discerning the moral status of FGC is due to its relationship to humanity and its connection to a larger framework, specifically the bioethical and global bioethics discourse. One scholar writes, “it’s the best way of thinking about ethical problems in health care permitting a thorough and systematic analysis of real bioethical problems.”³ The term ‘humanity’ is used here to refer to the condition of human beings collectively instead of individually. Specific to this dissertation, respect for autonomy is used as a guide in how FGC is ethically examined, and to discern the moral status of FGC. Some scholars writing about autonomy assert that autonomy is not absolute, and others argue that it should be one of the “first among equals of the four principles”⁴ creating subtle nuances which require rigorous reflection in an attempt to discern the moral status of FGC. One example of the nuances and the conflicting nature of respect for autonomy is the tension facilitated between the individual choice of the agent/actor, the health care professional, and their governing ethical code to observe the ethical guideline of non-maleficence, the focus of chapter six of this dissertation.

I. Understanding and Constructing respect for autonomy

This section will examine the scholarship on autonomy. Autonomy is held as one of the governing “moral principles in a framework of prima facie principles”⁵ that works within a larger bioethical context. Autonomy as one of the valued standard principles in bioethics involves the right of the patient/individual to determine their course of care. Furthermore, autonomy is respect for the individual’s wishes and life plan, which is to be honored. “[It is] at minimum, self-rule free from both controlling interference by others and from limitation such as inadequate understanding that prevents meaningful choice, such as inadequate understanding. The autonomous individual acts freely in accordance with a self-chosen plan analogous to the way an independent government manages its territories and sets its policy.”⁶ The notion of respect for autonomy can be a hard concept to understand when attempting to apply it to FGC. For example, women who are refugees have the right to make an autonomous choice to undergo the procedure. Application of autonomy to refugee women choosing FGC raises questions concerning how autonomy is reconciled with health care professionals who must respect the autonomous choice of the patient and honor non-maleficence.

The UNESCO *Universal Declaration on Bioethics and Human Rights* offers assistance in understanding respect for autonomy in an effort to provide good care for women experiencing FGC. Article 5: Autonomy and Individual Responsibility states: “the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others is to be respected.”⁷ The article in its most vital sense considers that all human beings are equal in dignity and are born free.⁸ Article 5, in addition, inspires several of the other articles having to do with rights, including informed consent, mentioned later in this chapter.⁹ What is different from the Georgetown bioethical treatment of autonomy is the mention of individual

responsibility for the choices afforded by autonomous decisions. Therefore, the patient is responsible for directing her course of care. Accordingly, not unlike the Georgetown framework of autonomy, the patient's viewpoint of her health circumstances, and her narrative take precedence in the relationship between the health professional and the patient. The patient's right to choose is a protection of her autonomy in that she is taking responsibility for her choices, namely the choice to undergo FGC surgery¹⁰

The consideration for the patient to take responsibility is critical to the care of women who choose FGC surgery. Its critical nature lies in the fact that if there is any disagreement between the health practitioner and the patient about her course of care, autonomy gives the responsibility to the patient, not to the health care professional. It is the responsibility of the health practitioner to respect the decision of the patient and to facilitate a positive outcome in care. Respecting the autonomous decision of the patient supports the aim of paying attention to and honoring patient preference and quality of life, two notions explored in the proceeding chapters. This consideration is particularly important in applying respect for autonomy, examined later in this section. In considering the application of autonomy it is important to note that the literature refers to autonomy in three distinct ways, the concept of autonomy, respect for autonomy and the moral principle of autonomy. The concept of autonomy is a concept used in a variety of disciplines that includes philosophy, theology, law, and in the field of bioethics. Autonomy is one of the valued standard principles in bioethics, particularly as it is used in the North American context.

Generally understood autonomy or individual autonomy refers to the ability to be one's own person, to live one's life according to the values, views and beliefs embraced by the individual, without manipulative, oppressive or external forces. In addition autonomy is

considered to be a principle derived from and based on a more fundamental principle, human dignity. Since human dignity is a fundamental principle, autonomy finds its justification and validation for its use in the human dignity framework.¹¹ While the human dignity framework is more fully examined in Chapter 6, since autonomy finds its validity in the human dignity structure a brief discussion is useful here to demonstrate its association. Regarding human dignity and human rights, the *Universal Declaration on Human Rights* affirms the dignity of all human beings, and recognizes that the “inherent dignity of all members of the human family is the foundation of freedom, justice and peace in the world, and is at the heart of most international human rights instruments.”¹² Further, [Article 3] of the UNESCO declaration includes human dignity as foundational to human rights and cannot be separated from the human condition¹³. Therefore when employing ethics to life situations, specifically health care, the efforts are to determine whether something is right or wrong and the movement toward what is good.¹⁴ In other words, the decision how morality would recommend care is given to the patient, namely women who choose FGC surgery and are in need of care.

As it relates to bioethics, the principle of respect for human dignity holds a place of prominence in the framework.¹⁵ Human dignity and human rights can also provide needed guidance on challenging issues related to health that affect people and populations of people globally.¹⁶ An example of how the framework gives direction on challenging health care issues is that the human dignity human rights framework can provide direction on the related health issue of FGC and the women who choose to undergo the medical intervention. Autonomy and freedom are an integral part of the western culture. In western culture autonomy is related to the ideal of independence, an ideal central to the cultural heritage of North America.¹⁷ The origins of the word come from the Greek term “auto” which means “self” and “nomos” which means “law, to

govern or to rule”¹⁸ and was first associated with governmental rule and the law. Autonomy, literally, is “self governance and has acquired meanings as diverse as liberty, privacy, individual choice and even economic freedom.”¹⁹ In other words, autonomy is the freedom afforded to individuals to live their own life, in their own way, on the condition that it does not bring harm to others and does not violate the rights of other people. Articulated in a different way, autonomy is the right to self-determination.

Other definitions of autonomy are useful in garnering an understanding of autonomy. For instance, according to Jacob Rendtorff there are five meanings of autonomy: “1) autonomy as capacity of creation of ideas and goals for life, 2) autonomy as capacity of moral insight, “self-legislation” and privacy, 3) autonomy as capacity of decision and action with lack of outer constraint, 4) autonomy as capacity of political involvement and personal responsibility, 5) autonomy as capacity of informed consent.”²⁰ Rendtorff further describes autonomy as a principle that should be regarded as “the self legislation of rational human beings taking part in the same human world and does not exclude the recognition of pluralism.”²¹ Not excluding pluralism is particularly helpful when constructing an understanding of autonomy that assists in respecting the autonomous choice of particular others whose choices are influenced by cultural beliefs, values, and practices that may be different from the health care professional. One such practice is FGC surgery. Self-legislation can be regarded as self-rule or agency. In other words, agency is making a choice on one's own behalf.

More specifically, as autonomy and respect for autonomy relate to healthcare, it is embraced as essential. Respect for the autonomy of patients protects them from abuse or exploitation. In the care relationship the person being cared for is in a dependent position, which makes them easy targets to serve the interests (e.g., financial, academic, or social influence) of

others. Within the specific context of the patient-professional practitioner autonomy contributes to the balanced and equitable patient-doctor relationship. By honoring the wishes of patient the patient directs the course of his or her care. Concerning the use of the word autonomy the bioethics scholarship characterizes autonomy as agency, as a way of illustrating an individual has the right to choose. A more formal definition of the term agency is the capacity of individuals to act independently and to make their own free choices.²² While individual autonomy is described as the right to self-determination, bioethics expands the use of the concept of autonomy to respect for autonomy.

Respect of autonomy is a medium by which the practitioner's conduct is in the framework of supporting the autonomous decision of the patient. In other words, "the autonomy of autonomous individual to make decisions is to be respected."²³ The notion reaches further than a viewpoint, or perspectives on respect, it is respectful action. What I mean by respectful action is that the health care professional does what it necessary not to impede or become a barrier to the autonomous decision of the patient. Additionally, respect for autonomy includes expressing appreciation for the right of individuals to embrace views, intentions, to make decisions and to live based on their values and belief. Respect for autonomy then is to respect the individual autonomy of others and to acknowledge their right to embrace views, beliefs, and values of their choosing. Further, employing respect for autonomy means that respect is given to the right of individuals to make decisions, life plans and take action based on their beliefs and values, even when there is disagreement between the care taker and the cared for. There is an obligation to do so. Therefore it is incumbent on the health professional to afford the patient the right to choose by honoring the wishes of the patient instead of becoming a barrier.

The distinctive feature of respect for autonomy requires that the health professional does not interfere with the decisions made by the patient. The practitioner acts in a way that acknowledges the value and the right of the patient to make decisions and empower them toward autonomous action.

A third and more distinctive use of the concept of autonomy found in the literature is the moral principle of respect for autonomy. The moral principle of respect for autonomy refers to recognition that individuals have a moral right to one's own decisions and to independent thinking. It is a right to self-governance. The moral principle of respect for autonomy recognizes that every individual is a moral agent with moral teachings and standards that are not imposed by outside forces, rather these are standards and guidelines employed by the moral agent herself. Another feature to the moral principle of respect for autonomy is that the principle takes into account various conditions that contribute to the inability for self-determination or autonomous choice. The bioethical scholarship refers to this inability as incompetence. There are several groups of people often referred to in this way and include the mentally ill, older people who suffer from confusion, people who have learning difficulties, people who suffer from trauma and children. The principle of moral autonomy asserts that there is a moral obligation for the health care professional to make sure that patients are capable of making authentic decisions concerning their life plan that can determine directions for care. Autonomous decisions depend upon autonomous individuals being able to make decisions. There can be no autonomous decision without capacity. Respect must be given for the capacity of the individual to decide.

The scholarship on autonomy suggests that depending on the theory, there are other features and characteristics of individual autonomy. Some of these features include the "abilities, skills or the traits of the autonomous person."²⁴ While the features of the diverse theories are

noted, they are not fully considered here. The consideration here is individuals who have the abilities, capacity, skills and traits to make autonomous decisions, i.e., decision making that leads to autonomous choice of women who choose to undergo FGC.

According to Beauchamp and Childress respect for autonomy can be articulated as having both a positive and negative features.²⁵ As a negative obligation, the concept necessitates that the autonomous action taken by an individual is not subject to the restrictive influence and control of others. As a guide for the practice and the application of respect for autonomy, there are specific perimeters employed for particular contexts. The scholarship describes concerning these specific boundaries that respect for autonomy “will need specification in particular contexts to function as a practical guide to conduct and appropriate specifications will incorporate valid exceptions that may affect rights and obligations of liberty.”²⁶ The negative obligation helps the practitioner to stay clear of dogmatic directives that include definitive and at times harsh language that can be a barrier to the application of respect for autonomy.

Respect for autonomy as a positive obligation demonstrates honoring of the opinions and values of others without condition or prejudice, especially when disseminating information that will assist in helping the patient to make decisions based on their life plan. The consideration of respect for autonomy is particularly beneficial in the case where a decision is made by the patient to take action that could invoke judgment or prejudice. One example of an act that may engender criticism and intolerance is, refugee women who do not accept the idea of eradicating FGC, but favorably embrace the traditional practice and intend to make the decision to be circumcised. The judgment and prejudice evoked make for a care environment where competing interests between the cared for and the practitioner are present. For this reason, respect for autonomy is critically important and a useful framework when reconciling the competing

interests of the healthcare professional and the patient, specifically healthcare practitioners who encounter women experiencing FGC.²⁷

The intention of the patient may be considerably different from what the health care practitioner can understand or agree. It is at this place in the relationship of care, that respect for autonomy is respect for the action taken by the individual rather than just a “respectful attitude”²⁸ toward the individual preferences of the patient. Respect for autonomy then includes respect for the autonomous action of the individual, namely the patient preferences investigated later in this chapter. It is the right of the patient to determine their course of care.

i. The Legal Framework of Autonomy

This section examines the bioethical tenet of respect for autonomy. However, while the notion of autonomy is an “ethical prescription, it is also predicated on the fact that it is a legal precept.”²⁹ The section will review how the legal structure applies to the bioethical framework and the contribution to bioethical conversation regarding autonomy. The ethical consideration of autonomy is a framework that affords protection to every human being in general, and specifically for women who are refugees and who choose to be circumcised, and so must be considered when discerning the moral status of FGC and how care will be framed.

The autonomous choice of individuals is ethically significant because autonomous choice manifests the value of personal autonomy that is deeply rooted in our culture. There is a “moral and legal right to choose and to follow one’s plan of life.”³⁰ To be sure, the bioethical precept of autonomy is not only a bioethical one but a legal construct. As described in the prior section, the genesis of the word, namely the Greek work ‘nomos’, means law and to govern. In other words, nomos means the right to decide and to shape one’s life course. As it relates to health care it means to be able to direct one’s course of care. The legal tenet is also used to “regulate the idea

of self governance.”³¹ Central to the idea of autonomy in the context of the law is the right to privacy. Some of the legal scholarship explains about the term privacy that the right to individual autonomy is in addition referred to as the right to privacy. In a general sense, the concept of privacy is used in diverse contexts to describe a variety of rights and privileges. Most notably however, the right to privacy concerns the right of an individual to make personal decisions about his or her life, free government interference and control. Another term found in the scholarship concerning autonomy is the concept of liberty and is used to describe both autonomy and privacy. For instance, in the Fourteenth Amendment of the United States Constitution the word “liberty” is used. The term autonomy is not found in the Constitution. The Supreme Court however has used the Fourteenth Amendment of the United States Constitution to devise a right to privacy that includes the reproductive rights of women, a right relevant to the women highlighted in this dissertation.

As it pertains to law, the right to privacy concerns the right of the individual to make personal decisions about his or her life free from government control, that is, the right to individual autonomy. The right to individual autonomy in American law includes many aspects that effect the entirety of the individual and not just medical features although the medical features are present. These aspects may include “the right to marry, the right to have a family, the right to reproductive freedom, the right to bodily integrity, the right to ingest substances, the right to refuse medical treatment, the right to physician-assisted suicide, the right to co-habitation and the right to intimate association.”³² It is the right of individual autonomy that makes certain that individuals, namely refugee women who choose to undergo FGC, are afforded the right to make personal decisions concerning their bodies, for example the right to reproductive freedom.

While the right of reproductive freedom is encompassed in the law it is important to note that concerning FGC, it is against the law in the United States when applying FGC to minors.³³ On the other hand women who are not minors have the right to self-determination. This right to choose extends to the right of reproductive freedom, which includes FGC. The legal precept of autonomy is critical to the idea of refugee women being able to choose to undergo the FGC. Autonomy gives agency to women to decide what to do with their bodies even when the decision is not embraced by the dominant cultural construct in which refugee woman live (contextual marginalization). In medical ethics however, the right to decide is protected by the law. The protection mentioned is safeguarded by another concept used in the framework of the law and in bioethics, informed consent. This concept protects the right of the patient. Both autonomy and informed consent are crucial to refugee women in safeguarding their right to choose without interference from others namely, health care professionals.

ii. Informed Consent

The doctrine of informed consent is one of the major features of healthcare ethics. The ethical purpose for informed consent is to protect the preferences of the patient in which care is being administered. Informed consent prohibits unwanted and unwarranted medical interventions and is therefore an indispensable prerequisite for medical care and biomedical research. As reflected in the section on the legal framework of autonomy, informed consent also has legal underpinnings. In fact, it is law that influences medical ethics. Since American law is based on justice and liberty, informed consent is understood as an expression of respect for autonomy and self-determination. It is the “willing acceptance of a medical intervention by the patient.”³⁴ Another feature of informed consent is to provide the patient with all of the information necessary that allows the autonomous individual to make a careful and well-informed decision

on his or her own behalf.³⁵ Since autonomy is the right to self-determination and to determine the course of care, informed consent assures that the construct of autonomy is adhered too. Informed consent is the means in which the preferences of are articulated.

One of the robust debates found in the scholarship on FGC is that the procedure is at times done without the consent of the parents. The FGC literature highlights that there are some women who flee from FGC communities and seek asylum in non-FGC communities so that they and or their young daughters do not have to undergo the procedure.³⁶ It goes without saying that these women have not given consent for the procedure. This approach is against their will and ethically not acceptable. While young girls are not the focus of this dissertation, they are mentioned here to highlight the argument for the eradication. The focal point and the attention here however is women, namely refugee women over the age of eighteen living in non FGC communities who choose to have the procedure and the generations of daughters who have the choice to undergo the procedure. Informed consent then will apply.

While informed consent would apply, there is a concern that women who choose will be provided with unbiased and accurate information that assists them in making an informed choice. Adequate information and full disclosure is one of the standards of informed consent that must be shared by the health care practitioner. The implication for informed consent and FGC, particularly in the US is that those who are involved in the care of the women must be able to disclose accurate and unbiased information regarding the FGC. Informed consent is applicable to the FGC procedure and refugee women who choose, as it underscores the need of the health care professional to be knowledgeable about the procedure. Whether performed by traditional practitioners, midwives or physicians, FGC is a medical intervention and is therefore subject to the rules and framework of bioethics. Therefore the autonomous individual for the medical

procedure, namely FGC, must give informed consent. However in the contexts where FGC is often performed the informed consent construct is not applied. Therefore informed consent is relevant when applying the doctrine to women who will choose the procedure, rather than being done against the individuals will. The doctrine of informed consent is relevant to future generations of women who will also choose to undergo the procedure. Informed consent can serve as an avenue by which women are informed and can be used as an avenue by which potential harm is minimized.

While informed consent has certainly evolved, the concept is now focused on protecting the autonomous choice of individuals. As it relates to refugee women whose autonomous choice is to undergo the procedure, employing informed consent as one of the frameworks for the ethical analysis of the traditional custom, gives way to not only to providing education, it also facilitates the need for health care professionals to be educated, trained and to have sufficient knowledge and understanding about FGC.³⁷ When thinking about the practical application of informed consent to women who choose to undergo FGC, one scholar notes about informed consent “informed consent is the practical application of respect for the patient’s autonomy.”³⁸

II. Applying Respect for Autonomy

In light of need for the practical application of respect for autonomy, particularly as it relates to refugee women and their choice for FGC, consideration of first and second order autonomy is a noteworthy and notable provision. Second order autonomy places importance and takes into account the cultural concerns of the individual receiving care. The second order autonomy construct lends itself to meaningful application to refugee women and the generations of women to come because of the centrality of cultural concerns, an idea elaborated further in chapter 6 of this dissertation. To be clear, second order autonomy assists the healthcare

practitioner to make room for diverse cultural values and beliefs that will influence the life plan and healthcare decisions of individuals. For example, the scholarship on autonomy notes particularly as it relates to women, that autonomy or the lack thereof is linked to the role of women manifested throughout different cultural contexts.

In many cultures, women have been socially dependent upon family, especially their husbands, sons and at times other family members. One example of the dependence of women on their husbands and sons is the deferment of decisions regarding their course of care. This deferment of decision-making, especially when it is a medical deferment is an example of “second order” autonomy. Second order autonomy as described by James Childress is “persons who are subservient to church or state would lack self-determination (first order autonomy) regarding the content of their decisions and choices because of their exercise of second order autonomy i.e., selection of the institutions in which they are subordinate.”³⁹ The distinction made between first order and second order autonomy is important to the investigation of FGC. Its importance lies in the rationales and reasons related to the traditional ritual, namely the connection to the institution of religion, religious beliefs and customs.

Therefore when applying first and second order autonomy to women who choose to undergo FGC and she verbalizes that one of her reasons for choosing this life plan is to honor her religious tradition and beliefs, she employs second order autonomy. Applying respect for autonomy to women who choose to undergo the surgery, includes the recognition that individual autonomy is rooted in society and history and may influence the autonomous decisions of individuals. An example often highlighted in the bioethics scholarship concerning both religious history and society is cases concerning Jehovah Witness. An example often highlighted in the bioethics scholarship concerning both religious history and society, are cases where the patient is

a Jehovah's Witness. The life plan of an individual embracing this particular religious tradition refuses a blood transfusion based on their religious belief and tradition that gives everlasting life precedence over life on earth if the latter can be sustained only by a blood transfusion. To be sure of the influence of societal and historical impact, an additional example that is raised from the bioethics scholarship concerning autonomy and choice is abortion. As it relates to religion, a woman may exercise her second order autonomy by choosing not to have an abortion to save her own life. She makes this choice because she embraces the values and beliefs of her religious choosing, namely the Catholic faith tradition. Having chosen this faith tradition she places value and depends on the teaching of her religious faith to inform her decision to forgo the abortion.

It is here that the notion of 'relational autonomy' is perhaps useful. Relational autonomy centers on the conviction that people are socially rooted. The characteristics and personalities of individuals are developed within the context of social relationships and influenced by and shaped by social determinants, that as race, ethnicity, class, and gender. However, as it applies to the application of respect for autonomy and to the autonomous choice of individuals, it is critical to take into consideration individuals have the right to use their autonomy as they desire, even if it means that individuals refuses to assert self-determination. In this way allows for the practical application of respect for autonomy to refugee women choosing FGC to be one where relevant aspects of autonomy are employed. Specifically, it makes room for the individual to decide and for the healthcare professional to take into account that how autonomy is asserted is "that the amount of autonomy exercised may differs depending on the person and the culture in which they are accustomed. These aspects of autonomy have relevance when considering the life plan and intention of refugee women who choose FGC.

What makes the application relevant is that refugee women who have settled the U.S. have done so in a non-FGC environment. Her life plan according to her values and beliefs will be different than those women who do not live in a non-FGC environment. Refugee women choosing FGC will employ their values and beliefs to come to this autonomous decision. Since individuals are influenced by the society and culture in which they live, the decisions made about ones life plan contains the principles, beliefs and values embraced by others. When investigating the application of respect for autonomy to women who choose to undergo the surgery the consideration includes what the literature describes as “a reasonable outcome of a decision”⁴⁰ along with other criteria in which autonomy is exercised.

These criteria are an effort to ensure the ability of individuals to make decisions. It is important to note however that there are groups of women who lack the ability to make decisions. Young girls under the age of eighteen are one group who lack the ability to make autonomous choices. As it relates to FGC, girls who live in FGC communities according to the literature often undergo the procedure and do so involuntarily. As noted earlier, these circumstances are unethical and unacceptable. While the aforementioned group of women is not the focus of this dissertation, women who have the ability to assert autonomous choice are, but unearth a possible dilemma. The dilemma is found in the application of respect for autonomy among women whose intentions are counter cultural to the dominant culture, --a culture in which they now live and receive care where the objective of care is a reasonable outcome.

The evaluation of a reasonable outcome is most often done by the healthcare professional. However, in the context of FGC as indicated in the scholarship on FGC, the health care practitioner most likely will lack knowledge and understanding of the surgery and may have a fierce opposition to the surgery. The difficulty is that the assessment of what is reasonable and

rational is made from the perspective of the health practitioner. This perspective conceivably creates a difference of opinion about the outcome of the decision. Because of the difference and perhaps the strong disagreement between the healthcare professional and the patient, specifically women who choose to undergo the procedure, there may be difficulty on the part of the health professional to honor and apply respect for autonomy.⁴¹

Concerning the difference of opinion regarding care some scholars argue that great care must be given as to not diminish or sabotage the right to self-determination. This is true particularly when the autonomous decision maker wishes to decide differently from the health profession. Applying respect for autonomy helps to resolve different experiences, values and world views between to healthcare practitioner and the person in their care.⁴² It is here that the values, beliefs, and cultural aspects are contributing factors in the application of respect for autonomy and therefore needs a broader perspective beyond the traditional dominant culture viewpoint.

i. Feminism and Respect for Autonomy

One criticism of autonomy is that the concept is dreadfully paternalistic. In bioethics particularly the dominant construct of autonomy situates human beings as self reliant and independent. This dominant viewpoint of autonomy ignores the reality that we are also interdependent making it difficult to employ respect for autonomy. The criticism is especially applicable to healthcare when the healthcare practitioner usurps the liberty to choose from patients, particularly women. In fact, as it concerns healthcare the feminist scholarship explains that health care providers have consistently ignored and misunderstood the needs and desires of the women in their care. In responding to the needs of the specific group of women under investigation, namely refugee women making the decision to undergo FGC, the reality of the

paternalistic posture described in the literature needs redressed. A feminist hermeneutic and framework brings awareness and reality to the value and worth of women. It affirms the capacity and intellect of women to make coherent decisions.⁴³

Women have intrinsic worth and goodness, are equal to men and have equal value to all human beings. Women embody the capacity for insightful and discerning activity. Therefore, the feminist construct of autonomy calls for a revision of individualistic conceptions of autonomy through ideas of relational autonomy highlighted in an earlier section. This reconsideration using the relational autonomy framework establishes that people are interconnected and interdependent and that the individuality and selfhood of people are rooted and shaped in the context of social relationships. Individual characteristics are not formed in a vacuum rather are shaped by a host of intersecting social determinants, such as race, class, gender, and ethnicity. The feminist framework takes into account the presence and influence of social and political critical to examination in this dissertation. It is the womanist framework however that works to examine the social determinants of race and ethnicity so critical to the subject matter in this dissertation and examined further in Chapter seven (7).

A second criticism of autonomy described in the scholarship is the tension between the individualistic tenor in which autonomy is often applied, and the interconnectedness of people, which creates what is called “social-self.”⁴⁴ The friction and restlessness present is the fact that the self’s very identity is determined by communities of which one is part, that is the pervasive influence of parents, peers and culture. There are two conditions for autonomy. These conditions are liberty and agency. As it relates to liberty and agency, some scholars articulate that an ad hoc committee needs to evaluate particular political arrangements and their adequacy for diverse and social context, while facilitating the two conditions necessary for autonomy. It is the evaluation

of political and diverse social contexts that the distinct features of feminism, and womanist ethics converge to bring the needed examination as a means for new paradigms for the ethical praxis for the employing respect for autonomy, particularly as it is applied to care.⁴⁵

Even as respect for autonomy is associated with patient care and with healthcare, autonomy is experienced in bioethics as extraordinarily independent and doesn't affirm the communal life and the development of person's overtime. Attention to the development of persons over time is critical to the future generations of refugee women who are from FGC communities and will make the decision to undergo the procedure. It is at this point that the idea of community is illuminated. While community is explored later in this chapter it is noted here to affirm the connection of identity to how the social self is shaped and influenced by community.

The interconnection allows us to appreciate how each relationship an individual participates in fosters or inhibits individual autonomy. The interdependence of individuals is how the feminist and womanist frameworks encourage observing respect for autonomy and have sought to reconstruct ideas concerning autonomy. For example in the spirit of interconnectedness Womanist ethics call for "communal lament."⁴⁶ In other words, in an effort to discern what morality would have us to do, the womanist construct embraces the relevance of identity and the social self, which are often influenced by a larger context, namely community. The employment of this approach to respect for autonomy is attentive to the social location and cultural context of women and respects the actions and life plans of individuals influenced by other social location and contextual features.

Conversely however, the feminist and womanist scholarship argue that at times these accounts of social location and contextual features can contribute to the oppressive socialization and oppressive social relationships that can impair autonomy, a sentiment often communicated in

the scholarship on FGC. An example of this impairment for instance is seen thorough forming an individual's desires, beliefs, emotions and attitudes and impeding the development of the capacities and competencies essential for autonomy."⁴⁷ Although respect for autonomy is critical to care, it is important to mention these challenging nuances that are present given the influential nature of community life, and the interdependence of individuals. It is the womanist framework specifically however that intentionally seeks to deconstruct oppressive socialization and oppressive social relationships, while employing the themes of relational autonomy. These themes establish that the core of our identity is determined by the community of which one is a part and by the influenced of other people, peers and culture. This influence is foundational to the development of agency, particularly among refugee women who often live in vulnerable communities. The contribution of feminism and the womanist framework to refugee women who choose FGC allows for the consideration of the full range of influential human relations, both personal and public.

ii. Community and Individual Autonomy.

When thinking about individual and community autonomy the scholarship offers a useful construct when considering the nuances of the relationship between community and individual autonomy. The discourse on community autonomy and individual autonomy is as times framed in the context of participatory research where community autonomy is related to cultural knowledge.⁴⁸ Article 5 in the UNESCO *Universal Declaration on Bioethics and Human Rights* further illustrates that these limitations; that is, the hindrance of or interference with individual autonomy by cultural features would constitute disrespect for fundamental freedoms.⁴⁹ This however does not mean that the community, in which one is intermingled, does not have a measure of influence on the individual who is asserting autonomy. Notably there is a communal

influence on individuals, as people are social being associated with contexts of a social nature. Nevertheless, it is when there is the absence of coercion or manipulation that an individual is free to voluntarily make the autonomous decisions.

The idea of the interference of individual autonomy is courteous, especially as it is concerned with prohibiting a woman from making an autonomous decision- that is the legislative action to “ban or disallow” a cultural practice such as FGC. Interestingly, some countries and communities in Africa have used legislation as a tool to prevent FGC.⁵⁰ However, community or cultural autonomy might suggest that individuals have the autonomous right to enjoy, develop, and take part in their culture.⁵¹ This right is particularly recognized when the cultural practice does not infringe on the human rights and the autonomous rights of others. Women who make the autonomous decision to undergo FGC surgery do so as a result of their life plans, which include beliefs and values that are inspired by the culture and community. To infringe upon the right to enjoy cultural features seems insupportable. In fact, Gerald Mackie explains, regarding the culture practices and customs of community, “you simply can’t outlaw cultural practices, it is not possible to criminalize the entirety of a population or the entirety of a discrete and insular minority of the population”⁵²

Many African countries have banned FGC. To date, 15 African countries passed legislation that specifically bans it.⁵³ However, in 2015 Nigeria introduced a new federal law banning all forms of FGC.⁵⁴ Does the legislative ban on FGC interfere with the autonomous right of women to participate in their culture? Do these laws inhibit the right of a community, particularly one that embraces FGC, to develop their cultural customs including diverse reasons for the decision to undergo the surgery? The research supports that women favor the continuation of female genital surgeries⁵⁵ and desire to embrace the cultural traditions in which

they live. It is important to note here that preserving the autonomy of a community is not the case when a cultural practice is imposed against the will of an individual. In fact, performing any medical intervention without permission and against the will of the individual is ethically unacceptable.

Much of the feminist scholarship explored in the earlier section affirms that the Western framework for autonomy is rendered individualistic and does not consider the influence of the much wider context of community. One of the approaches examined and referred too earlier in this dissertation is relational autonomy, which takes into consideration the social identity and the intermingling of relationships that are nurtured in the context of community. In exploring care for women refugees who will make the autonomous choice to undergo FGC, the link to community is a critical consideration. Making the connection to community is an important consideration. Its significance is found in the rationales and reasons attributed to FGC, specifically the community of faith and the strong communal context in which individuals are nurtured and belong.

When working with refugee women who have migrated from close knit communities the connection between individual autonomy and community autonomy are pertinent since the behavior of individuals are deeply embedded in the communities value and belief system. This close bonded nature of community is particularly true in Africa where communities are connected by a strong sense of family pride that includes generations of family, namely the ancestors and long cultural traditions. One such cultural tradition is FGC, a cultural tradition embraced for years. In view of the fact that there are communal dimensions to identity and the social self, and a strong extended family and community exists, it is understandable then that the viewpoints, values and beliefs are transmitted through the context of community from one

generation, ethnic group or tribe. Since individuals are both interdependent and independent the idea of competing interests are again probable and illustrated earlier in this chapter. The interests in competition are the interests perhaps of community and the intentions of the autonomous individual. For example, these competing interests, (that values and beliefs of the community and the intention and interests of the individual), conceivably arise when making the decision to undergo FGC surgery in a community where the values and beliefs are vastly different.

It can be said that the same competing interests arise when there is a deviation from the social norms and behaviors constructed in the society in which individuals are shaped and live. An illustration of this deviation is when the intention of women currently living in a FGC community do not intend to undergo the FGC surgery. The interest of the community and the individual intention of the autonomous individual compete. It is in reflecting on the conflicts of competing interest that the scholarship provides an inclusive approach where the interests of the community and the individual do not necessarily have to compete. One feature of respect for individuals is “respecting persons as an independent end in themselves.”⁵⁶ However, autonomy does not imply that the life plan that an individual chooses excludes the interest of others, namely community. The identity and the social self of individuals is formed in community and no matter how different the life-plan or autonomous choice is it doesn't exclude the interests of other, namely the community.⁵⁷

The community and individual autonomy has further implications that are specific to refugee women who choose FGC and the health care practitioner. As it relates to the community autonomy of healthcare professionals and interests that may be different than those of refugee women choosing FGC, there are compelling competing interest that must be investigated. However, as it relates to autonomous decisions, the notion of voluntariness must be considered

even when there is a vast difference between the intentions of the patient and the understanding and action of the practitioner.

iii. Voluntariness, Autonomy and Care

The concept of voluntariness has become an important feature in bioethics⁵⁸ and is one basic dimensions of the concept of autonomy. It is employed as the second element of informed consent and third of three conditions of autonomous action.⁵⁹ Voluntariness as it relates to the individual receiving care must be in a position to have the power to choose without outside control or coercion. Additionally, voluntariness is the ability of the individual to determine the desired intention without being under the controlling interference of another person, illness or disorder that can diminish voluntariness. An example of diminished voluntariness is a person who is mentally ill and unable to volunteer. Mental illness can interrupt an individual from autonomous choice and intention.

Voluntariness is a concept salient to the notion of care, particularly when applying the concept to the autonomous decision of those whose healthcare decisions and intentions may not be a normative one. The idea of voluntariness is particularly relevant to refugee women who live in cultures where FGC is not part of the established norm and who will voluntarily undergo the procedure. Chapter one of this dissertation established that for women to undergo FGC surgery involuntarily is ethically unacceptable. On the other hand however, the scholarship on FGC makes clear that there are women who embrace the surgery and who voluntarily undergo the medical intervention.⁶⁰ Since the surgery is historically a cultural tradition that is transmitted from one generation to another, one ethnic group and community to another, it is probable that there will be future generations of women who will also embrace their cultural tradition and will voluntarily undergo the surgery.⁶¹ The concept of voluntariness is useful in this context of care.

The notion of voluntariness describes acting in accord with one's intention. When employed by an autonomous individual, the person has a desire for a specific action and is compelled to do so without being swayed, or under authority or domination of another.⁶² It is important to mention although not addressed in this dissertation that the mental or emotional condition is at times a concern and must be taken into consideration. One of the queries that are raised when considering the notion of voluntariness concerns the intentions of the individuals influenced by outside factors. For instance, are the intentions or life plans of an individual influenced by one's values and beliefs or are they influenced by the interdependence of community and culture in which we live?

In the previous section of this chapter the notion of influence was examined and it was determined that there are factors that influence an individual's autonomous intention. These factors include the social determinants such as gender, ethnicity, and the values and beliefs of the community in which an individual belongs. With respect to voluntariness, being influenced by non-coercive values and actions does not mean that the life plan or the intention of the individual is not an autonomous one. The investigation on influence further determined that the decision of the individual should not diminish and that care must be taken to respect the autonomous wishes of the individual. Furthermore, due to the nature of the social-self and the social-identity of individuals, it is impossible for them not to be a certain measure of influence.

Nevertheless, it is crucial to note that according to the scholarship on the voluntariness in the bioethics literature, influences are both negative and or positive.⁶³ Negative influences are associated with coercion, also a subject often reflected in the discourse on FGC. Coercion is most often associated with a threat. It is at this juncture that the influence becomes a negative one. Importantly, the idea of coercion exists only when the "intended and credible threat

displaces a person's self-directed course of action."⁶⁴ When the displacement of an individual's intention occurs the decision is no longer an autonomous one.

This understanding of negative influences and coercion is particularly useful when it is associated with the autonomous choices of individuals especially as it relates to ethical decision making about one's healthcare, namely FGC. When the autonomous decision is made that is not normative, meaning the decision does not attend to the standards of the established norm, the idea of influence is assumed to be a negative one. An example is the controlling influences of the healthcare practitioner who is providing care for a refugee woman who chooses to undergo FGC. Not only is there an opportunity for disagreement between the patient and the healthcare profession there is also a chance for the health practitioner to refuse to provide care. The refusal becomes a controlling influence that can thwart the voluntary intention of the woman receiving care. The notion of controlling influences is a theme that draws robust debate in the scholarship on FGC. However a noteworthy observation is made in exploring the scholarship on FGC. The focal point of controlling influences is often toward the community ethos in which women who have experienced FGC live, rather than negative influence of the practitioner.

Since the notion of voluntariness is associated with autonomy and providing care, the health practitioner must take precautions not to become the actor in the controlling influence. To facilitate voluntariness, positive influences are employed, namely the type of treatment and actions that foster autonomous decision making. Therefore when providing care the healthcare professional must be careful not to impose on one's self directed intention. As it relates to future generations of young women who will have intentions to undergo FGC surgery the idea of voluntariness is critical when applying it to care of women who will choose.

III. Applying Respect for Autonomy to Care

In the field of bioethics there are moral theories and approaches that serve as a framework and guide for determining moral and ethical decision-making.⁶⁵ While the ethics of care is more fully examined in chapter seven, the notion of the ethics of care lends itself to a framework for care in which to work and to apply respect for autonomy. The approach of the ethics of care asserts that there is a persuasive moral significance of attending to and meeting the need of particular other in which we take responsibility. In other words, it is in the context of the relationship (ethics of care) between the practitioner and the cared for that the needs of the patient is realized and attended too. The scholarship further explains about care, “care is in the first place a relationship between individuals.”⁶⁶ It is within the relationship of the caring professional and the patient, namely refugee women who choose to undergo FGC that need for the application of respect for autonomy to her care is essential.⁶⁷

Respect for autonomy is intimately linked to the notion of care. It is connected by the relationship between the cared and the cared for. Caring for other is the primary goal of health care. The aim of healthcare is further articulated as the improvement of quality of life for all those who need and seek care. While quality of life is not a topic explored in this dissertation it is important to note that this is a goal of care and calls for further examination. One way to consider the connection of care and respect for autonomy is through the features of patient preferences (autonomy) and how patient preference contributes to applying respect for autonomy to care. The scholarship on patient preferences describes patient preferences as “what is essential to care.”⁶⁸ Since patient preferences can also be articulated as autonomous choice, the preferences of the patient become the ethical “nucleus”⁶⁹ of the relationship between the health professional and individual receiving care.

There is an unmistakable ethical significance to patient preference, i.e. autonomy that is critical to care, but especially to care for the group of women represented in this dissertation. The scholarship further explains that patient preferences are ethically significant because they manifest the value of personal autonomy that is deeply rooted in our culture. This is particularly true and challenging for women who are refugees and choose to undergo FGC, and for the future generations of women who will also choose to employ their beliefs and values associated with the cultural custom. Respect for autonomy can be challenging in the practical application because the ethical ask of a woman to be circumcised is not a surgery familiar to the US and most likely becomes an obstacle for exercising respect for autonomy and care. One challenge perhaps is that the practitioner has little to no knowledge about FGC. Another difficulty related to employing respect for autonomy to care is the difference in the values and beliefs between the healthcare professional and the woman choosing to undergo FGC surgery. This difference can cause disagreement about the course of care for the patient and the ability of the healthcare professional to respect the preferences of the patient, i.e. the autonomous choice of the patient.

It is here that an additional feature of patient preferences (autonomy) highlighted in the scholarship is useful. This characteristic is referred to as the “expression”⁷⁰ of an individual’s intentions and life plan. This feature of expression as it were, is influenced by the social context in which the patient is situated. It is in this light that Rendtorff’s illustrations of the limits of autonomy are useful as there are “tensions between the human existence as unencumbered self and the embodied, embedded character of human existence.”⁷¹ The embedded quality of human life is the reality of human existence and applies to women from FGC contexts who now live in non-FGC environments and choose to undergo the medical intervention.

The idea of patient preferences is critical when considering care for women who choose FGC and who are in need of care. The critical nature of patient preferences for this group of women lies in the fact that autonomous choice is influenced by culture and social context. For example, FGC is a ritual that conveys meaning in a variety of ways depending on the cultural context.⁷² Furthermore, with FGC, as in other cultural traditions, for example, the embedded belief in not accepting blood transfusions honored by Jehovah's Witnesses mentioned earlier. A second illustration of social contextual influences is the absolutely unacceptable medical intervention of abortion revered by those who embrace specific religious traditions. These perspectives are inspired by the context of culture. In fact, the preferences and health decisions of patients are motivated by "cultural and religious beliefs."⁷³

The preferences of the patient are fundamental to good clinical care, and especially to women who choose FGC.⁷⁴ Mentioned earlier, according to Jonsen, Siegler and Winslade, the wishes of the patient have substantial ethical importance.⁷⁵ Their importance lies in the fact that the desires or wishes of the patient make clear the value of personal autonomy that is deep-seated and established in culture.⁷⁶ One reason that the preferences of the patient are an integral part concerning the care of women is the recognition of the desire of women who choose FGC shows respect for the value of their personal self-rule and agency in medical care.⁷⁷ A second reason that patient preferences are important is the fierce opposition to the practice in the U.S. The disapproval of FGC can cause not only disagreement highlighted earlier but can facilitate the patient's vulnerability in the context of care.⁷⁸ While vulnerability is the subject of Chapter 6 it is relevant to the autonomous choice of women who choose FGC, especially in a non- FGC environment like the U.S.

When thinking about vulnerability in the context of health care, and particularly as it relates to women who choose FGC in non-FGC contexts, the point in which vulnerability is associated with care is protecting those whose autonomy is in danger of being jeopardized.⁷⁹ An example of protecting women as it concerns care is, protecting women from ridicule, judgment and the refusal of being able to undergo the medical intervention. When autonomy is threatened and ignored, the preferences of the patient are disregarded. The overlooked wishes of women who choose FGC surgery impede the moral right to make choices about ones own life intention. In addition, to discount the right to self-legislation affects the future generations of women who will choose to participate in their culture, namely to undergo FGC surgery as an expression of their autonomous life choice.

In other words, patient preference is this expression that gives meaningful voice to the autonomous intentions of the cared for. It is meaningful because it further facilitates the application of respect for autonomy to care, and prioritizes the expressed desire and an individuals life plan which includes culture, religious beliefs, and value. Patient preferences and the expression of the preferences of the individual “contribute to decisions about care.”⁸⁰ It is the preference of the cared for that is essential to good care, namely care for women presently, and future generations to come who will choose a life plan that includes FGC.

IV. Conclusion

The concept of autonomy is used in a variety of disciplines that include philosophy, theology, law and bioethics. In fact autonomy is one of the pillars that shapes the bioethical framework in which to support ethical decision-making and assists with employing standards on the best way to practice ethics as it relates to providing healthcare.⁸¹ It is a valued standard. In bioethics it is the right of an individual to determine their course of care. Further, autonomy is

literally self-governance and the freedom of individuals to live their own lives, in their own way. Autonomy is the right to self-determination. Autonomy is central to the idea that personal autonomy encompasses self-rule that is free from controlling interference by others. Autonomy is both a legal construct and a bioethical one. It is the legal aspects of the idea of autonomy that includes that of reproductive rights intimately connected to refugee women who choose to undergo FGC surgeries and must be respected

Applying respect for autonomy means to acknowledge and respect that individuals have a right to make decisions based on their values and beliefs and that “such respect involves that actions toward the autonomous individual are respectful. The respectful action applies especially when there are differences in the values and beliefs of the health care practitioner and the patient. The health care professional must take care not to become a controlling influence that derails the intention of the women who voluntarily chooses to undergo the FG surgery. The voluntariness of individuals will be influenced by social determinants prevalent in the context of community. Because individuals have both a social self and social identity, being influenced cannot be avoided. However these influences do not mean that the autonomous choice of the individual is any less autonomous. Therefore the preferences of the individual must be honored. It is essential to care.

Respect for autonomy is one sure way of meeting the health care need of women presently and the future generations of women who will choose FGC. Maintaining respect for the individual receiving care keeps the relationship focused on the woman receiving care. Furthermore employing the notion recognizes the intentions and the life plan of the patient. In this way respect for autonomy is connected to care. This relationship of the carer and the cared for fosters the basic goal of health care which is to facilitate the quality of life for the patient

which is done through respecting the life plan and intentions of the cared for, namely refugee women who choose voluntarily to undergo FGC surgery.

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Chapter 4: Non-maleficence, Beneficence, FGC and Care

The significance of exploring the ‘moral status’ of FGC/c rests in the alleged physical harm associated with FGC often described in the scholarship. The health consequences associated with FGC surgeries raise specific dilemmas for both the health care practitioner and the refugee women who experience FGC and are in the care of the health professional. The argument advanced in this chapter is consideration for the use of the idea of non-maleficence, as it is part of the health care ethics framework that assists in ethically examining FGC and determining what care for women who undergo FGC should be. The concept of non-maleficence has implications for healthcare professionals who encounter women who, with intention, voluntarily choose to undergo FGC. The chapter is devoted to working through the notion of non-maleficence, its application, its nuances and the implications for healthcare professionals. The following questions help to shape the discussion: might there be certain types of FGC/c procedures that present less harm and risk than others, and if so, how can health professionals cooperate with practices that inflict various types of harm particularly under the guide of the non-maleficence framework? The chapter will conclude with how non-maleficence can influence the model of care for women experiencing FGC.

I. Non-maleficence

In advancing the notion of non-maleficence, this section will examine what the bioethical construct is and survey how it is applied to women refugees and FGC. Non-maleficence is both a concept and a principle. Conceptually, non-maleficence is described as the avoidance of harm or the infliction of the least amount of harm as possible to reach a beneficial outcome. The primary goal of non-maleficence, however, is to “do no harm.”¹ On the other hand, the principle

of non-maleficence designates a moral obligation to refrain from inflicting harm. As it relates to healthcare ethics the health care practitioner has an obligation and duty not to harm those who are in her/his care. In the larger framework of health care ethics, non-maleficence plays a critical role in patient care. For example, according to Jonsen, Siegler, and Winslade, the principle of non-maleficence is linked to the quality of life maxim, and it is the patient who determines what is harmful and what is not.² The concept of non-maleficence is closely related to the concept of beneficence. The concept of beneficence refers to mercy, kindness, and charity and symbolizes actions intended to benefit the well being of others. Benevolence, which is associated with beneficence, is the attribute and characteristic of an individual and denotes the qualities and nature of a person inclined to act on behalf of others. These actions are beneficial rather than harmful. The concept of beneficence does not reflect obligation or duty.

The principle of beneficence, however, describes the moral obligation to act for the good and well being of others.³ Even though the principle of non-maleficence and principle of beneficence are closely related, there are distinctions- namely that there is a moral obligation to refrain from harm (non-maleficence) and a moral obligation to act to benefit others (beneficence). Some scholars organize non-maleficence and beneficence together to form one single principle.⁴ For example, Frankena's approach to non-maleficence, examined later in this chapter, arranges the principle of beneficence into four obligations with the principle of non-maleficence being last. Nevertheless, these two moral obligations raise a moral conflict and serve as competing interests because both principles are involved in caring for patients, namely refugee women who choose to undergo FGC surgery. Specifically, the conflict facilitated by the principles affects the health practitioner who must take care to refrain from harm and take positive actions to help others⁵ which involves allowing the patient to determine what is harmful

and what is not. The vastly different viewpoints become evident when the preference of the patient is to choose to risk the harm associated with FGC surgery, while the obligation of the health practitioner is to practice non-maleficence. By employing the two principles conflict emerges; the patient's perspective on the idea of harm and what the patient may view as positive steps to help her obtain quality of life.

The patient's perspective on what indicates harm is critical as it relates to care for refugee women experiencing FGC.⁶ Her perspective and outlook concerning her care is what Jonsen, Siegler and Winslade refer to as patient preferences.⁷ The significance of the preferences of the patient rests in the fact that patient preferences are "essential to good clinical care"⁸ specifically, care for refugee women who choose FGC surgeries. This is not to say that the patient and the health professional do not agree that the procedure of choice, FGC, may cause harm. In fact, nearly all surgeries, according to the scholarship, have a level of expected injury.⁹ The two opposing points of view held by the actors are the conflict between the patient and the health care practitioner as it relates to the wishes and the care of the patient-refugee women who choose to undergo FGC surgery.

The second conflict that emerges when considering non-maleficence (to do no harm) and beneficence (to take positive steps to do what benefits the patient) is the quality of life for the patient. It is said that quality of life is the most fundamental goal of medical care.¹⁰ One area of tension when considering quality of life is that the patient ultimately determines it. The development of any disagreement on quality of life is based on what the patient determines as quality of life verses quality of life as judged by the health practitioner. The idea of surgery, i.e., FGC, which brings no health benefits would be difficult for the health practitioner to associate with contributing to the quality of life for the woman choosing FGC surgery. In the context of

FGC it is plausible that the physician providing care may be biased toward a lifestyle that includes FGC.¹¹ Therefore the biased judgment of the health care practitioner concerning quality of life for the patient may be influenced by negative attitudes and can affect her/his clinical judgment about quality of life. These significantly differing viewpoints do cause conflict between the patient and the health care professional. The two differing points of view raise ongoing ethical questions about how to proceed with care, the focus of this dissertation.

The idea of quality of life is a subjective construct. Since the maxim can be an individualistic and personal construct supported by opinion, it can be difficult to define. However Jonsen, Siegler and Winslade, define quality of life as a "multi-dimensional construct that includes performance and enjoyment of roles, physical health, intellectual functioning, emotional state, and life satisfaction or well-being."¹² The axiom also is referred to as a judgment.¹³ Given the definition offered by Jonsen, Siegler and Winslade, the opinion of what quality of life means is influenced by the personal assessment of the patient about how the autonomous choice to undergo medical intervention, namely FGC, will affect her life. What the patient brings to the personal assessment of what quality of life means are her beliefs, values, culture, and customs. It is these cultural features that assist her in determining quality of life.¹⁴

Since quality of life is defined as a framework that embodies various aspects, which include the pleasure and satisfaction of societal roles, and fulfillment of life and well being, curiously, quality of life could be observed as a cultural construct, a subject examined more fully in chapter 5 of this dissertation. Interestingly however the societal role of women is one of the rationales attributed to FGC. The connection of quality of life for the patient, specifically women who choose FGC is a noteworthy consideration in exploring what care should be for women whose life plan includes FGC.

In the bioethics framework quality of life includes the ethical construct of personal autonomy investigated earlier in this dissertation. Quality of life is an expression of one's own life course and closely linked to patient preferences.¹⁵ Quality of life then is a critical consideration for examining what the care should be for refugee women who choose FGC. It is in this light, quality of life, that autonomous choices are made and that wishes of the patient are honored. For women choosing FGC surgery, the principle of beneficence facilitates positive steps to the well being of the patient. Moving toward a model of care for refugee women who choose FGC that includes autonomous choice and quality life are foundational to beneficence.

In assessing the principles of non-maleficence and beneficence, particularly as it relates to the care of refugee women choosing to undergo FGC, the scholarship considers that at times, the obligation to refrain from harm can be inflexible, more so than the duty to help.¹⁶ However, depending on the medical circumstance, the opposite can apply. For instance, if the health care practitioner makes an incision which causes tenderness and bleeding to allow air so the patient can breathe: then the "obligation of beneficence takes priority over non-maleficence."¹⁷ While this scenario may be plausible, some of the scholarship on the principle of non-maleficence cautions that generally non-maleficence trumps beneficence.¹⁸ In spite of this caution, the typical override is not absolute, and the emphasis placed on non-maleficence depends upon the circumstances. In other words, the circumstances will dictate how the principle of non-maleficence is assigned and applied. Conversely, there will be times depending upon the situation that beneficence will override non-maleficence.

An illustration of a circumstance where the principle of beneficence has priority over non-maleficence is a case where a patient has a life threatening allergic reaction. The health

practitioner administers a needle that inflicts minor harm for the major benefit of saving the life of the patient. The ethical priority for the consideration of the principle of non-maleficence is important. The significance lies in the harmful consequences often claimed and associated with FGC. It is important to note that the use of the terms harm and injury here are used generally to mean “incurring or at an increased risk of incurring pain.”¹⁹ One issue in the debate over FGC is the harmful consequences associated with the practice. The alleged harm endured by women who undergo FGC includes, but is not limited to physical complications for example severe pain and bleeding and long-term complications.²⁰ In contrast the research informs that the alleged harmful consequences are over emphasized and inaccurate by mainstream narrative.²¹ This raises the question of whether harm and injury are associated with most invasive medical interventions, i.e., FGC discussed earlier in the chapter. According to Gillon, there is risk of harm to patients in most medical interventions.²² Drawing on this argument by Gillon the query is raised whether the alleged harm associated with FGC is due to surgery in and of itself, or whether the harm is related to unskilled health workers and the absence of adequate medical care. If it is the later, then non-maleficence obligates to reduce harm and beneficence suggests that reducing harm is acting on behalf of women who choose FGC. Avoiding harm is “untenable”²³ and non-maleficence cannot take priority over beneficence.

The principles of non-maleficence and beneficence have moral implications as they concern the care given to patients, particularly when the care involved may invoke a certain amount of injury observed in the previous paragraph. Some examples of care that may invoke harm highlighted in the scholarship include, intending and foreseeing harm; killing and allowing to die; and withholding and withdrawing life-sustaining treatment.²⁴ While these scenarios are not the focus here, they represent authentic and tangible examples of moral dilemmas present

when considering the principles of non-maleficence and beneficence. The scenarios also bring to light the ethical dilemmas and nuances present in the investigation of refugee women who will choose to undergo FGC and will be in need of care.

One compelling moral implication of non-maleficence and beneficence related to what the focus of care should be for refugee women who choose FGC surgery is mitigation or lessening the alleged physical health consequences often associated with FGC surgery. Investigated earlier in Chapter 1, FGC is distinguished by four types of cutting. The observed types of FGC surgeries are also assigned degrees of injury.²⁵ For example, Type I and IV surgeries are described as the surgeries that involve the least amount of cutting.²⁶ Type I surgery is known as Sunna and is characterized by Sheldon and Wilkinson as the one FGC surgery that may not entail “necessary or permanent injury.”²⁷ Type IV surgery is described as ‘unclassified’ and is also comprised of less invasive forms of cutting. Examples of Type IV FGC surgery include pricking or piercing of the clitoris and/or the labia and at times includes small cutting.²⁸

The implications for both Type I and Type IV surgeries are that these two surgeries not only lessen the assumed injury involved, Types I and IV allows for the health care practitioner to honor both the non-maleficence and beneficence construct. Considering the frameworks of non-maleficence and beneficence for Types I and IV supports the focus of care of what care should be for women who are choosing FGC surgery. This focus on what care should be is facilitated by honoring the autonomous choice of the patient and taking actions toward positive outcomes that not only support the quality of life for the women choosing FGC, but also afford the health care practitioner to refrain from harm, i.e., employing the principle of non-maleficence.

Another implication for employing the principles of beneficence and non-maleficence observed through the lens of remediation is that remediation fosters prevention of the alleged

harmful consequences associated with FGC surgeries, namely types II and III. Types II and III cutting are described as the most severe of the surgeries and present the most long-term health complications.²⁹ Being able to lessen the harm by using less invasive interventions, namely Types I and IV, contributes to help to frame a response to the ethical tension between the health professional who is concerned with non-maleficence (do no harm) and the patient whose life intention is to undergo FGC surgery.

Concerning the ethical response to FGC, health professionals are uncertain of the medical ethic, do no harm.³⁰ According to Rebecca Cook, FGC surgeries are safer under the guide of medically trained professionals rather than unskilled and unprepared hands.³¹ Considering non-maleficence in this way supports shaping a construct of what the care should be for women who choose FGC. For example, employing medically trained hands to perform FGC surgeries, particularly the less invasive surgeries, facilitates a decrease in injury that contributes not only to the harm reduction framework, but also gives skilled professionals the opportunity to become an actor in beneficence; to contribute to the positive outcome for the patient. Since a positive outcome would be garnered by the lessening of injury, it is critical to observe minimizing harm as “an aspect of non-maleficence.”³² Minimizing the harm, i.e., the health consequences associated with FGC surgeries as a feature of non-maleficence is embodied in the Hippocratic Oath.

A. Hippocratic Oath

The principle of non-maleficence is one of the four pillars in the framework of bioethics presented by Beauchamp and Childress and is frequently used in the FGC scholarship as a way of drawing ethical conclusions regarding FGC that lead to eradication.³³ Obajulu Nnmuchi, for example, writes, “the ethical principle of non-maleficence is directly related to the health

consequences of FGM-and requires health professionals to “first do no harm.”³⁴ The argument used, employing non-maleficence, asserts that, because of non-maleficence or “do no harm,” eradication is the only response to FGC. Perhaps the lack of investigation regarding the principle of non-maleficence generates a response that is unbalanced and biased. These prejudiced assessments and understandings serve as a barrier to the right of women to choose FGC and for care to respond favorably to their intention. In an effort to understand the maxim it is perhaps useful to survey the exegetical landscape of the axiom often missing in the scholarship on FGC.

The principle of non-maleficence is often attributed to the Hippocratic oath and to the maxim *Primum non-nocere* which articulates, “Above all [or first] do no harm;” however, according to the scholarship on the maxim, non-maleficence is not in the oath.³⁵ In fact, *primum non-nocere* is not part of the Hippocratic Oath at all. Regarding the expression however, Albert Jonsen explains that the Hippocratic Oath expresses a similar sentiment, which asserts that physicians will not use their skill, knowledge and abilities to injure or wrong their patients but will use their skills and any treatment to help.³⁶ The scholarship further describes that while *primum non-nocere* or “do no harm” does not appear in the Hippocratic Oath, the axiom “do no harm” is found in the Hippocratic literature called the Epidemics, a collection of observations made by Greek physicians while they assisted with the therapeutics of medicine. It is important to note that, when translating from the Greek text, the text, at times, does not allow for the translation of all words, leaving the translation of the meaning of the word altered. Nevertheless, Beauchamp and Childress write about the Hippocratic Oath that the oath “incorporates both an obligation of non-maleficence and an obligation of beneficence”³⁷

According to Robert M. Veatch, the Hippocratic Oath is part of what is called the Hippocratic Tradition. The tradition began as a movement in Greek medicine. Veatch explains

that the Hippocratic Oath is a collection of writings often referred to as the Hippocratic corpus. Not all writings in the corpus are of an ethical nature; however, the Hippocratic Oath is, and it contains an oath of secrecy as well as a set of moral imperatives.³⁸ The most celebrated and well known of the rules and obligations is the idea that “the physician ought to act so as to benefit the patient and keep the patient from harm according to the physicians ability and judgment.”³⁹ An additional and significant observation, unearthed in the analysis of the maxim and important to the choice of women to undergo FGC, is that the “above all” phrase was not added to the “do no harm,” expression. Rather, the “above all” axiom was added to the phrase that refers to help and benefit. Consequently, the maxim read, “the physician must aim above all at helping the sick; if he cannot, he should at least not harm them.”⁴⁰

Curiously, the scholarship related to the “do no harm” adage emphasizes that the proverb, if you will, is meant more toward helping the patient rather than doing harm.⁴¹ This does not mean that “do no harm” is not justifiable, and reasonable, it is, rather, it serves to say that medicine and the use of surgery are designed to affect a change for the physical well-being of the patient⁴² and not for the intended purpose of harm. In light of this exegetical help, the maxim is better served to say, the expression makes the well being of the patient the priority. The expression also guides the health professional to secure good and that which is beneficial to the patient, rather to prioritize and place emphasis on “do no harm.” This is not to say that the principle of non-maleficence does not obligate the health practitioner not to do harm, but rather the principle of non-maleficence obligates the health practitioner to first consider the well-being of the patient, do what is beneficial for the patient (from the patients point of view), and to garner what is good. In parsing out the principle, it is clear that non-maleficence is nuanced particularly because, in benefiting a patient, at times harm, is encountered.⁴³ One example of the nuances and

difficulty in understanding non-maleficence is the idea for instance, of the doctrine of double effect, examined later in this chapter. It is important to highlight here, however, that double effect “incorporates an influential distinction between intended effects and merely foreseen effects”⁴⁴ often present in the context of surgery, namely FGC. Distinguishing the differences in the two principles is helpful, particularly in examining what the care should be for women experiencing FGC. Specifically, the principle of non-maleficence refers to the obligation to refrain from inflicting harm to others.⁴⁵ On the other hand, the principle of beneficence can be explained as the opposite of non-maleficence since the principle of beneficence is the obligation to contribute to the welfare of others and to take positive steps to help others⁴⁶. The principle of beneficence refers to the moral obligation to contribute to the well-being and to the good of others.

Differentiating the principles assists in determining what care should be for refugee women who choose FGC surgeries. However, in the work of distinguishing the two principles some scholars writing about the principles of non-maleficence and beneficence articulate non-maleficence as an aspect of beneficence,⁴⁷ a framework used in Frankena’s hierarchy of non-maleficence and beneficence.

B. Frankena’s Hierarchy of Non-maleficence and Beneficence

The principle of non-maleficence is used in the scholarship on FGC as an “absolute obligation from which no detour is permitted.”⁴⁸ Non-maleficence applied in this seemingly malignant and unbalanced way suggests there will always be a negative consequence without consideration of the beneficial outcome for the patients who choose FGC surgery, therefore leading to a conclusion that surgery or a medical intervention of any kind should not be done. However, upon further inquiry into the principle of non-maleficence a more balanced and

realistic approach is constructed.

William Frankena's representation of non-maleficence assigns non-maleficence as a part of the beneficence framework. In this schema, beneficence is the highest aim. It is the obligation to do good, and to prevent evil or harm and suggests that if there was no basic obligation to do good, then there would be "no duty to realize the greatest balance of good over evil."⁴⁹ Therefore, the ideal is to do only good and not evil. However, in healthcare, it is an unrealistic endeavor to ascribe to the ideal to "do good only" and not to "do no harm."⁵⁰ At times, some harm is experienced in attaining the greatest benefit. Since this is the case, Frankena explains that the principle of utility offers and presupposes a more basic obligation, of which is to produce good and prevent harm. Therefore, the "principle of beneficence asks us to actually do good and not evil."⁵¹ Non-maleficence then, in Frankena's hierarchy, places the principle of non-maleficence as part of the larger principle of beneficence, which is the moral obligation to act for the benefit of others. For Frankena, the lowest level of beneficence is the obligation not to inflict harm. In ascending order, his representation of the principle of beneficence, which includes non-maleficence, is described in the following way:

1. Do not inflict evil
2. Prevent evil or harm
3. Remove evil
4. Promote good and do good

Interestingly, in Frankena's representation of "do no harm" he affirms the exegetical parsing out of Hippocratic oath where the emphasis on "above all" in the treaty is to "do good."

Importantly, Frankena's meaning of beneficence becomes relevant in working with refugee women who live in non-FGC communities and choose to undergo FGC surgery. It is relevant in two ways. First, Frankena's hierarchy embodies the UNESCO Universal Declaration on Human Rights, which grounds both rights and ethics in the inherent dignity and equality of human

beings. Further, “inherent dignity is the property of being human that generates the universal moral obligation to do good for, and avoid harm to, other humans and the fulfillment of that obligation is the basis for the principle of beneficence and non-maleficence.”⁵² Secondly, the relevance of Frankena’s framework of beneficence lies in the priority of promoting positive steps to help others and to promote good, a framework perhaps when applied has fewer negative connotations for women who intend to pursue FGC surgery.

II. Beneficence and FGC

This section examines the principle of beneficence using Frankena’s hierarchy and the application of the principle to refugee women who choose to have FGC surgery. In the preceding section, a review of the literature explains that the notion of non-maleficence is often linked with the concept of beneficence. For example, as scholars describe in health care, practitioners have to consider and weigh the two principles together.⁵³ While this linkage is an integral part of Frankena’s framework, Beauchamp and Childress argue that there is a distinction between the principles of beneficence and non-maleficence. They should therefore be separated into two principles and not melded into one.⁵⁴ In addition the research describes that the major feature of the principle of beneficence is that provision is made, and support is given to contribute to the well being of others.⁵⁵ Frankena’s structure of beneficence does not deny that the focus of beneficence is toward the benefit and good of others, but rather the good and benefit of others is prioritized and is the first element in his framework, while non-maleficence is last. However, in the mainstream framework, the principles of beneficence and non-maleficence are separated and applied separately.

Therefore in exploring what the care should be for women who choose FGC, Frankena’s framework for beneficence is persuasive particularly for health care practitioners providing care.

The implication is that Frankena's schema considers non-maleficence as an aspect of beneficence. In other words, Frankena's framework prioritizes beneficence. Prioritizing beneficence in this way underscores the centrality of autonomous choice of patients and the outcome of quality of life and well-being for the women whose life intention is FGC. The principle of beneficence affirms, "morality requires us to make positive steps toward assisting others, and not merely to refrain from harm."⁵⁶

Making positive steps in an effort to help refugee women who will choose to undergo FGC will require applying the principle of beneficence as articulated by Frankena. Since the principle of beneficence is a moral obligation to contribute to the welfare of others and to make positive steps to help others, the idea of reducing the harm that is at times associated with FGC, and numerous other medical interventions found in healthcare, is a noteworthy consideration. Harm reduction is one way to apply the principle of beneficence to the care of women who choose FGC. The construct allows for lessening the harm associated with the surgery. In addition harm reduction is an avenue in which to take positive steps to benefit the patient and to honor the autonomy of the patient and to engage in care that brings benefit to the patient.

A. Harm Reduction

In determining what the care should be for women who voluntarily choose to undergo FGC surgery, the notion of harm reduction is a meaningful concept to consider. In considering this concept the specific focus is whether the harm associated with FGC surgeries can be lessened and even prevented by guaranteeing safe medical procedures, and if so, whether harm reduction is a worthy consideration. According to Bettina Shell Duncan, the idea of guaranteeing safe medical procedures is not new to the debate and faces fierce opposition by those who advocate for the eradication of the practice.⁵⁷ It is "activists, as well as many international medical

associations that largely oppose measures to improve its safety.”⁵⁸ The opposition to improve the safety of the surgeries raises the query regarding FGC of whether the disapproval is related only to the health consequences or whether there are other objections unrelated to the surgery. The research describes that there are other areas of resistance that may be related to the unfriendly response to harm reduction. While these areas of opposition are not investigated here, it is important to mention, as they are related to the larger discussion on FGC and harm reduction. Nevertheless, if the surgery can be done in a way that reduces harm it has implications both for healthcare professionals and for women who voluntarily choose to undergo FGC.

One implication is that harm reduction quite possibly facilitates guidance for health practitioners who encounter women who intend to pursue FGC. Another implication is that the surgery can be done in a way that prevents harm incurred by unsanitary and non-medical environments that can cause damage to patients. As it relates to the harm reduction and positive outcomes for the patient, it is important to approach FGC as the medical procedure that it is, therefore ethically bound to all of the standards, processes, values, and norms that other medical procedures adhere too.

In doing so, the UNESCO Article 4 [Benefit and Harm] offers a framework for thinking about and living with the risks of harm. While there is a moral sanction that entitles every human being to be free from intentional harm, absolute protection against all harms is not attainable, even in the best of circumstances.⁵⁹ In the aim toward medical treatment that has both a positive and beneficial outcome, there is a high probability of unintended harm. Therefore, it is important to point out that without a certain amount of unintended yet probable harm, the advances in medicine and life saving treatment would not exist. Article 4 of the UNESCO framework also makes clear that the possibility of harm is morally acceptable when the benefits are maximized

and the harm is reduced.

Since there have been small successes made in the eradication of FGC and an increased suspicion that the occurrence of FGC in the US is more frequent than previously thought,⁶⁰ harm reduction is a worthwhile and credible response. According to Nancy Kass, harm reduction is based on the assumption that when there is an underlying cause of a health problem or health burden which remains difficult to eliminate, intervening to reduce some of the adverse harmful consequences of the problem, namely the health consequences associated with FGC, can result in lessening the harm.⁶¹ In other words decreasing the alleged harm related to FGC can result in a “net reduction in harm”⁶² for individuals and the wider community. Therefore, harm reduction according to the Article 4 in the *Universal Declaration on Bioethics and Human Rights*, is morally acceptable as the idea of harm reduction is to minimize harm, particularly the harmful consequences associated with FGC surgeries.

Nevertheless, there is a balance between benefits, harm and risk.⁶³ There are many kinds of benefits associated with benefiting the patient. In healthcare ethics, for example, benefits are a positive value; however the term is associated with the anticipation of the prevention of cost and the decrease of risk. Further, positive benefits can be seen as directly related to the patient and include the interests of the patient and the wider community to which the patient belongs. Another benefit that can serve the health practitioner is the knowledge of the health professional, which will be of benefit to present patients and also future patients, in particular future generations of women and daughters who will choose FGC surgery. Some scholarship explains that benefits can support the development of policy, which can nurture progress for the common good.⁶⁴ Based on the trends of eradication and the current focus on the prevalence of FGC in the U.S., certainly the development of more balanced policy concerning FGC is in order.

On the other side of benefits are risks. Risks are the assessments and estimates of the probabilities and chances of injury to either the patient or society and are deemed a negative value. An example of risk and risk to society is the Tuskegee experiment. The Tuskegee experiment produced harm, which violated the welfare and interests of the patients and the society at large. In healthcare ethics risks are also defined as a “set back to the interests of the patient, particularly in life, health, or welfare.”⁶⁵ This particular characterization of risk is compelling. It is compelling because the definition affirms that the idea of risks in health care is not only associated with the chance of occurrence of physical harm, but also puts risk in the context of the interests of the patient. Positioning risk in this context is an important consideration when working with refugee women who will choose to undergo the surgery, particularly in a health care setting where the health care practitioner may make biased and unbalanced value judgments about the physical risk and harm to the patient without considering the interests of the patient.

Harm must be evaluated in the context of the financial burden of the patient, along with the emotional and spiritual harm of the patient. Further consideration of the financial burden of women who choose FGC is imperative. The significance of reflecting on financial aspects of the lives of refugee women who choose FGC surgery lies in the reality that one of the primary rationales for FGC is related to the cultural construct of marriage. Marriage, particularly in Africa is associated with family honor, economic well-being and financial security of women, however proof of virginity is a prerequisite for marriage.⁶⁶ Since the financial security of women is connected to marriage, FGC becomes the central avenue and method for ensuring marriage and honoring family.

Harm reduction is characterized as an avenue to address the primary cause of a health

problem that is difficult to eliminate. In addition, the harm reduction approach involves interventions that will reduce adverse harmful consequences. The research on harm reduction asserts that the harm reduction methodology can be seen not only as eliminating harm, but also as a way of garnering steps to improve lives,⁶⁷ particularly the lives of women experiencing FGC surgery. The harm reduction approach can result in the lessening of harm of FGC surgeries and therefore is applicable to FGC. In the investigation of harm reduction, harm reduction assumes that the strategies to reduce the harm, namely health consequences related to FGC, can garner even incremental improvement in the outcome, and incremental improvement is to be valued. Medicalization is one such strategy to reduce the alleged harmful consequences of FGC.

B. Medicalization of FGC

Medicalization is a term used in the FGC scholarship to refer to the characterization of FGC as a medical condition.⁶⁸ Formally, medicalization is a process by which human problems come to be defined and treated as medical problems.⁶⁹ Medicalization involves the human experience, which includes culture, social context, personhood, and the like. Considering the medicalization of FGC, as it is a medical procedure is not new to the FGC discourse and remains an affront for some who advocate and develop strategies for eradication of the practice.⁷⁰

Medicalization of FGC has a strong relationship to beneficence. The connection lies in the responsibility of the health professional to change what can be changed while continuing to find ways and approaches to address larger changes. According to the UNESCO Article 4,[Benefit and Harm] changing what can be changed is the practical response.⁷¹ Therefore one of the practical responses to FGC is medicalization. The idea of addressing larger changes in FGC is clearly noted in the FGC scholarship. One such change, for instance, that is highlighted in the literature is the eradication of the FGC.⁷² While eradication was explored earlier in this

dissertation, it is critical to mention again here, since the larger change particularly as it relates to the health consequences associated with FGC could be addressed by medicalization.

Advocates for eradication argue that FGC is a violation of human rights.⁷³ The traditional custom is often characterized by those who support eradication of FGC as a form of violence against women.⁷⁴ One legal scholar notes that FGC must not be medicalized, but rather the practice must be criminalized and made punishable through the process of making laws to abolish FGC which will support “elimination and foster an environment that is intolerant to FGC.”⁷⁵ However, scholars argue that some of the legal situations to ban the practice are “ethically unsustainable.”⁷⁶ Similarly, the World Health Organization (WHO), other organizations, countries and nations have what is described as a zero-tolerance policy that claims that all forms of FGC must be eliminated immediately.⁷⁷ Further, other anti-circumcision advocates argue that medicalization is “not a step in the right direction since it does not imply a progression toward less severe forms of cutting.”⁷⁸ Conversely, however, Obiora contends that while the efforts to promote hygiene and sanitation through medicalization may not be the decisive or the final strategy for implementation, the idea of abolition is not the solution.⁷⁹ In addition, the FGC scholarship regarding medicalization includes proposals that argue for less severe forms of cutting, the use of anesthesia, and pre and post- operative antibiotics.⁸⁰ An example of cutting that is less invasive is demonstrated in some of the proposals for medicalization explained later in this chapter.

Ellen Gruenbaum explains that due to the culturally embedded nature of FGC, an idea investigated in Chapter Six of this dissertation, that FGC is not easily challenged⁸¹ even when the health effects and consequences are known making medicalization of FGC worthy a consideration. In communities where cultural custom is the dominant rationale behind the

practice, medicalization can be a “socially acceptable”⁸² approach. For example, forms of socially acceptable circumcision include the use of anesthesia and less invasive cutting by trained professionals, for instances pricking instead of cutting. In this way the harmful outcomes of FGC are reduced facilitating a positive outcome for women who choose the surgery.

In the effort to improve safety and the reproductive health of women who undergo FGC, medicalization is becoming increasingly common across Africa.⁸³ Efforts to implement the use of milder, less harmful forms of circumcision- particularly in the Sudan and Somalia- were introduced. In Somalia, for instance, “sunna” is encouraged and is now offered in health clinics operated by midwives who have been medically trained. Sudan also ascribes to “sunna,” a milder form of circumcision. The scholarship on medicalization of FGC further shows that in other countries in Africa where “medicalized” forms of circumcision are performed, the medicalization includes the dissemination of educational materials on FGC and other traditional practices.⁸⁴

According to the research the services of trained nurses are in high demand since the surgery has been medicalized by the use of sterile instruments and an anesthetic, which reduces pain and allows for more precise cutting.⁸⁵ An example of the high demand for medicalized FGC surgeries takes place in Kenya where FGC is illegal. Even though the custom is banned in Kenya, trained nurses perform the surgery on patients who are on leave from the Christmas holiday.⁸⁶ In light of the changing trends of FGC, specifically medicalization, research describes that some physicians practicing in Africa advise against having the procedure performed in the home as it is traditionally accomplished. The reasons explained for not performing FGC in the homes it is that FGC is a surgical procedure and “it would be just like having an abortion done in a clinic that is not legitimate or does not have good medical, surgical sterilization and other

practices.”⁸⁷

While the medicalization efforts in Africa are important to emphasize, the focus of this dissertation is on refugee women who choose to undergo FGC and settle in the U.S. Regarding medicalization of FGC in the West, for example, both in the Netherlands and in the U.S., efforts to minimize the health risks and outcomes of FGC through medicalization have been proposed.⁸⁸ Both proposals offered included a safer alternative to infibulations, the most invasive type of circumcision. For example, the FGC scholarship describes that in the Netherlands a plan was made to draw a distinction between circumcision that allegedly impairs tissues during circumcision and “non-mutilating ritual incisions.”⁸⁹ In addition, the Netherlands proposal included that healthcare practitioners be allowed to perform the surgery under anesthesia, making the surgery safer and less traumatic. The Dutch government rejected the proposal.

The “Seattle Compromise” was the second proposal in the West to medicalize FGC. In Seattle, doctors and nurses in obstetric practices were surprised and alarmed when “pregnant Somali women were asking physicians to circumcise both their boy and girl babies.”⁹⁰ The Somali mothers were also concerned about their adolescent daughters who had not been circumcised. Interestingly, the Somali mothers asked physicians to perform less invasive genital procedures. The women explained that if they could not have some form of the procedure performed on their daughters in the US that they would send their daughters back to Somalia where the most severe surgery would be performed, or they would have the procedure done in the US by an “imported traditional practitioner.”⁹¹ Concerned with the reported severe health consequences of the traditional practice of FGC, health practitioners in Seattle decided to try a new approach to surgery. The U.S. proposal involved consent by patients from Somali immigrant communities to undergo a less invasive and less aggressive form of the surgery.⁹² The proposed

procedure initiated a nick of the clitoris to draw a single drop of blood, and the surgery would be completed under anesthesia. Significantly different from the traditional way of performing FGC, namely with no anesthesia and more invasive cutting, the intense opposition and “aggressive lobbying by anti-circumcision activist”⁹³ impeded the proposal from coming to fruition. The 1996 plan for medicalization of FGC was abated.

Mentioned earlier, there is opposition to the medicalization of FGC surgeries. The research, however, describes that the opposition voiced against medicalization is seemingly without the consideration for how the medicalization of FGC advances patient safety and lowers the risks of reported health consequences of the surgery. This course of examination is critical. The seriousness of the consideration lies in the fact that the strategies designed to sanction the practice cannot be maintained, whereas medicalization of the practice can be the avenue in which FGC can be performed in a way that is medically less harmful.⁹⁴ To ignore medicalization, and engage in the ongoing opposition without considering the immediate benefits and positive outcomes of medicalized FGC surgeries continues to push the traditional custom and practice underground.

The research on medicalization and the improvement of health-related outcomes suggests that there is benefit to medicalization. In a study conducted by Bettina Shell- Duncan et al., the data shows that among traditional circumcisers (non medical persons in communities that perform circumcision) who use “sterile razors, anti-tetanus injections, and prophylactic antibiotics are associated with nearly 70% lower risk of immediate complications.”⁹⁵ Further, according to the data, it appears that given the outcome of the research at a minimum, small changes in FGC surgeries such as the implementation of medical interventions significantly reduce health consequences associated with FGC.

Medicalization of FGC is a worthy and compelling consideration. Reducing the harm associated with FGC is an ethical and practical response to harmful consequences often associated with the procedure. Medicalization embraces the tenets of beneficence, which is to improve health and make a positive step toward providing benefit to others, namely refugee women who choose to undergo FGC surgeries.

III. Obligation, Non-maleficence and Beneficence

A. Obligation, Care and FGC

The concept of obligation, specifically as it is connected to the principle of non-maleficence and beneficence, promotes an optimistic, less oppositional view and assists in answering the second query of this dissertation concerning how health care professionals should respond to the care of women whose intention is to undergo FGC surgery. While the two principles of non-maleficence and beneficence are different, in exploring the care of women the two concepts do converge. The convergence rests in the relevance and application of non-maleficence to refugee women and in the care using the framework of beneficence articulated by Frankena. Obligation is intimately connected to the principle of beneficence.

One of the questions raised in this dissertation is whether care implies that the physicians and healthcare professionals have an obligation to the specific health care needs of the female circumcised patient, or to the woman who intends to be circumcised. The scholarship on health care ethics highlights that health professionals have an obligation of non-maleficence, or “to do no harm.”⁹⁶ After the careful investigation of non-maleficence it is determined that non-maleficence is more accurately defined as a notion toward helping the patient rather than doing harm. The guidance inspired by the non-maleficence principle, or as it is called “do no harm” is to assist in the well-being of the patient, and to ensure that the results of care are beneficial to the

patient. Conversely, the scholarship on FGC makes no reference to the principle of beneficence as it relates to FGC. In the context of the patient-health practitioner relationship the health practitioner has an obligation to act in a fiduciary manner, namely the obligation of beneficence. Acting in a fiduciary manner consists of always and without exception favoring the well being and interests of the patient.⁹⁷

The principle of beneficence is associated with obligation, obligation with duty, and duty with demands. Obligation distinguishes the principle of non-maleficence and beneficence from the concept of non-maleficence and beneficence. While beneficence and non-maleficence create tension for health practitioners working with women who experience FGC surgeries, the principle of beneficence is a valuable ethical principle in determining the justification of the obligation. According to the UNESCO *Universal Declaration on Bioethics and Human Rights*, the obligation begins with the inherent dignity of every human being. Further, “inherent dignity is possessed equally by every human being and is the basis of equality of human and humans. Inherent dignity is the property of every human being that generates the universal moral obligation to do good, and avoid harm, to other humans. Fulfillment of that obligation is the basis for beneficence and non-maleficence.”⁹⁸ As the idea of obligation and commitment relates to the patient, namely refugee women who choose FGC surgery, it is incumbent upon the health professional to do good for the patient.⁹⁹ According to Frankena the first obligation is to do good.¹⁰⁰

Importantly, many acts of beneficence are not obligatory. Examples of non-obligatory acts are kindness, sympathy, and charity. Some may refer to these characteristics as benevolence. However, a principle of beneficence, in our use and application of the principle, establishes an obligation to help others further their important and legitimate interests.”¹⁰¹ Ross additionally

suggests, “Obligations of general beneficence rests on the mere fact that there are other beings in the world whose condition we can make better.”¹⁰² The idea that in a broad sense, beneficence lies in making conditions better for others is helpful. It is especially helpful when considering the practical application of the principle of beneficence as it presupposes an obligation to address FGC in two ways.

The first is that the principle of beneficence obligates the health profession to attempt to make FGC less harmful for those who choose the surgery. An obligation to make conditions better, to restore functioning, and to relieve pain and suffering is an active engagement in the process of beneficence.¹⁰³ The second is the application of Frankena’s approach to care. Frankena’s approach is critical, as it serves to make clear the level of beneficence that is needed to achieve the obligation. In Frankena’s approach using his hierarchy of the principal of beneficence does not deny the obligation toward the good of others; it is the first feature in his framework.¹⁰⁴ The lowest level is the obligation not to inflict harm, placing the level of obligation toward the good of the patient first.

Frankena’s framework for beneficence is compelling for the application of beneficence and care, particularly for women choosing FGC surgeries. In addition, Frankena’s framework has implications for the healthcare professional and care, namely that which morally requires us to “make positive steps toward assisting others, not merely to refrain from harm.”¹⁰⁵ However, the most critical component in the application of the principle of beneficence by the health practitioner is to fulfillment of the moral obligation to do good. In other words, it is the duty of the health practitioner providing care for women experiencing FGC to bring to fruition and to carry the obligation to do good. The achievement of beneficence rests in the hands of the health professional giving care. In this way, there is a more balanced and positive approach rather than

the more oppositional view often described in the FGC scholarship. It is a framework that has fewer negative connotations.

When considering the notion of care, particularly as it relates to obligation and FGC, scholars writing about care assert that there are aims and goals of care and depending upon the discipline, care is defined differently.¹⁰⁶ For the purposes of this dissertation, the goals of caring are to help individuals to achieve, at a minimum, the basic level of well-being, survival, and as much basic functioning as they are able to achieve. In addition, goals of care include helping to satisfy basic biological needs that are necessary for survival and basic functioning. Included in basic biological needs is the need for food, clean drinking water, a clean environment in which to live, shelter, clothing, and basic medical care.

In examining the idea of care, Joan Tronto offers ethical elements of care that are helpful in determining the obligation of the health professional to the refugee women who choose FGC.¹⁰⁷ According to Joan Tronto, there are four ethical elements of care; they include attentiveness, responsibility (different from obligation), competence, and responsiveness¹⁰⁸. As it concerns refugee women who choose FGC surgeries, each of the ethical elements have relevance for their care. However, due to the countercultural nature of FGC to the cultural context of the US, FGC is often met with judgment and lack of knowledge of the medical procedure. It is in light of the barriers of a deficiency of knowledge concerning FGC and the negative judgment associated with FGC that the idea of competence as an ethical feature of care is relevant. This is not to say that attentiveness and responsiveness are not important-they are. However, in discerning the obligation to meet the need of women experiencing FGC, the ethical element of competency to care is a priority.

Competence is an important feature in the FGC scholarship as it relates to FGC surgeries

and care. One of the debates in the FGC scholarship is that untrained medical practitioners often perform the procedure.¹⁰⁹ In addition, particularly in the West and most specifically in the U.S., the health care professional is not adequately trained to respond to women who have experienced FGC or those who will choose the procedure.¹¹⁰ According to Tronto, “to include competence as a part of the moral quality of care”¹¹¹ is critical. Its importance lies in the ability to provide care, and conversely, the inability to do so. The inability to provide care does not meet the obligation of beneficence and leaves the need for care unmet.

B. Refraining from Harm

Refraining from harm is central to the more mainstream understanding of the concept of non-maleficence and is the underlying focus of the “do no harm” maxim. This is not to say that refraining from harm is not included in the approach highlighted in this dissertation—it is. However, as mentioned the refrain from harm maxim is positioned in a way where the obligation is to “do good for others” first and then refrain from inflicting harm.¹¹² The alleged health concerns associated with FGC have made refraining from harm the focus of the eradication of FGC. Conversely, however, there are other approaches to FGC, namely the approach to reduce harm. It is important to mention that in the healthcare ethics scholarship refraining from harm is not easily accomplished.¹¹³ Gillion for example explains, that to ‘do no harm’ and “abstaining from harm is untenable.”¹¹⁴ One concept in the bioethical scholarship that is noteworthy to mention briefly when investigating the notion of “do no harm” or refraining from harm is the idea of double effect.¹¹⁵ The concept is not by any means fully exhausted here; rather it is emphasized and highlighted as another consideration when thinking about the idea of refraining from harm. Double Effect is also mentioned to denote that the idea of refraining from harm is at times used in the scholarship in a way that oversimplifies the maxim.

According to the rule of Double Effect (PDE), it is sometimes permissible to cause “harm” as a side effect of bringing about a good result, even though it would not be permissible to cause such harm as a means to bringing about the same good end.¹¹⁶ In other words, PDE is invoked when one act, which has a good effect and a harmful effect, is not always “morally prohibited.” An example highlighted by Beauchamp and Childress is a patient who is suffering from excruciating pain, and the physician wants to help. The patient asks the physician to help alleviate the pain by helping to end his life. If the intent of the physician was to alleviate the pain of the patient using medication, and did not intend to end his life, then the act of indirectly hastening the patient’s death is not wrong.¹¹⁷ David Kelly explains direct and indirect as “once actions have been analyzed by the PDE the action is considered either an indirect or direct act.”¹¹⁸ The PDE must meet four conditions; then the act is right. These actions according to David Kelly include:

- 1) the intended act-in-itself is not wrong or bad
- 2) the bad effect must not cause the good effect
- 3) the agent must not intend the bad effect (as an end to be sought)
- 4) the bad effect must not out weigh the good effect.

According to the PDE, acts that have both a good and bad outcome may be justified under certain conditions particularly when the effect out weighs the bad, and the bad that is done is not directly intended.¹¹⁹ Since FGC is often described as a surgery that is immoral and wrong, the PDE framework is useful in thinking about the care of refugee women whose choice is FGC and how PDE is observed in the context of FGC.

It is helpful to note that critics of PDE prioritize the total balance of good outcomes over harmful ones and that an appropriate intention is indicated by the mere fact that the proportionality, namely that the good out weighs the bad (that was permitted) in the outcome of

the act,¹²⁰ specifically FGC surgery. The positive outcome is especially applicable for women whose life plan is to undergo FGC surgery. The surgery is not only a positive outcome; it is also the preference of the patient.

In thinking about women who choose FGC, one of the rationales for the surgery is aesthetics and other socio-cultural reasons. Sheldon and Wilkinson write that defenders of FGC can clearly differentiate between the intended effects and those that are unseen.¹²¹ The cultural rationales for FGC, i.e., the enhanced chances of marriage and ascetics often described in the literature are the aim of the intervention or the act. Any injury that is incurred is considered a side effect- foreknown but not intended.¹²² The good effects are quality of life based on the personal autonomy of the woman choosing FGC surgeries, the enjoyment of social roles, life fulfillment, and well-being. The bad effects are perhaps the alleged loss of pleasure if infibulation is done. However, if Type I circumcision (Sunna) is performed, removing the prepuce without removal of the clitoris, fewer direct harmful side effects occur.¹²³ PDE gives another medium by which to observe the alleged harm and/or injury associated with FGC.

The scholarship on FGC describes several types of harm.¹²⁴ The physical harms have been expounded throughout the dissertation. However the other harms described in the scholarship refer specifically to emotional, psychological, and spiritual harm.¹²⁵ For instance, Loretta Kopelman found that “psychological disturbances in girls due to circumcision are not uncommon.”¹²⁶ The research explains that women, who had the surgery as children, and against their will, have psychological effects that can be characterized as anger and trauma.¹²⁷ The psychological effects have the ability to follow a person through their life. For some women, the effects of the psychological trauma include a breach of trust and confidence in family and community.¹²⁸ Other women, depending on their age, have a different experience.

When exploring the aforementioned effects of FGC on women who experience FGC surgeries, not all women share the same experiences. Ylva Hernlund explains, concerning psychological trauma, that the psychological impact and well-being of women who have undergone FGC requires more research.¹²⁹ It is important to note that the some of FGC literature that describes the psychological and the emotional effects of FGC are associated with largely with young girls and not with women who whose life plan is to have the surgery. Regarding the other harms mentioned above, there is little research found in the scholarship on the emotional, and spiritual harms of FGC on women experiencing FGC. The highlighted effects are namely the potential physical health consequences of FGC.

What is curious regarding the emotional and psychological effects of harm, however is whether these effects are due to the FGC surgery itself, or whether the emotional effects are due to the loss of autonomy when being forced to undergo FGC without consent. Regarding the effects of FGC surgeries on women, scholars note that more investigation is needed on the psychological effects of FGC on women.¹³⁰ Unfortunately, the alleged harmful psychological consequences of FGC are often used by anti-circumcision activists to promote allocations of harm associated with the surgery. Regrettably, not having a body of sound research that focuses on the psychological and mental effects of FGC, promotes the continued inconsistencies and inaccuracies that foster ongoing assertions that FGC is not only morally wrong, but also a violation of the maxim “do no harm.”

In spite of the sparse investigation concerning the psychological and emotional harm of FGC surgeries, there has been research in the abortion scholarship that gives some insight on the query concerning the emotional and psychological harm related to FGC. Similar to those who oppose FGC, the anti-abortion activists make claims that abortions harm women both physically

and psychologically.¹³¹ In addition, those who oppose abortion assert that abortion causes mental instability and even suicide for women who experience abortion, despite the rejection of this claim from professional mental health organizations.¹³²

According to Susan Cohen, anti-abortion activists will refer to studies that have flaws in the methodology and take advantage of the general public and policy makers who do not know what constitutes “good science.”¹³³ After a close investigation of the FGC scholarship examined in this dissertation, it appears that the attitudes of those who oppose FGC use unreliable research to legitimize and promote claims of harm, specifically physical and psychological harm.¹³⁴ One example of the over-accentuated, mainstream narrative regarding the harm that is linked to FGC, is argued by the Public Policy Advisory Network on Female Genital Surgeries in Africa. The Public Policy Network observes, “the widely publicized and sensationalized reproductive health and medical complication associated with female genital surgeries in Africa are infrequent events and represent the exception rather than the rule.”¹³⁵ Further, according to the research employed by Obermeyer and Reynolds they explain that harmful health complications are relatively rare occasions and that women who have experienced FGC surgeries encounter problems.¹³⁶ It is important to emphasize here that the contrasting viewpoint regarding complications and harm associated with FGC is critical in discerning what the focus of care should be for women who undergo FGC surgery.

An additional consideration concerning the psychological and emotional harm also highlighted in the FGC literature,¹³⁷ is found in the abortion research. It is useful and beneficial to note that the investigation on whether abortion posed a threat to the physical, emotional and psychological well-being of women concluded “the scientific studies do not provide conclusive data about the health effects of abortion on women.”¹³⁸ Given the aforementioned critique on the

alleged harm associated with FGC and the conclusions mentioned concerning harm and abortion, it is plausible then to expect that acting on behalf of others is met with accurate unbiased knowledge mentioned earlier in the chapter and an outcome that is positive in the life of the patient.

C. Acting on behalf of others

Acting on behalf of others is the essence of the principle of beneficence. In fact, the scholarship on the principle of beneficence refers to the principle as “the moral obligation to act for the benefit of others.”¹³⁹ The significance and the implication of the principle of beneficence is that the principle gives direction, guidance and action about how the concept is applied to refugee women who choose to undergo the FGC surgery. In addition to the significance of beneficence and how it is applied to women experiencing FGC, beneficence gives guidance for the care of women who choose to undergo FGC. As mentioned in a preceding section, one of the dilemmas raised by FGC in the U.S. is that the custom is quite foreign to the U.S. health care system. Due to the unfamiliarity of the traditional practice, the lack of knowledge about FGC, and the judgment associated with FGC, these elements create a dilemma for the health care professional about how to respond to women in need of care. Perhaps one of the primary characteristics in the care of women experiencing FGC is the responsiveness of the health practitioner.¹⁴⁰ However, it is not only responsiveness, it is also the response, namely to act on behalf of the other.

Responsiveness, as explained by Tronto, is considering the other person situation as the situation is expressed by that person, instead of making an attempt to put oneself into the other persons “shoes,” namely the patient.¹⁴¹ In this way, the health professional is involved from the perspective and viewpoint of the patient. Given the countercultural nature of FGC, especially in

the context of the U.S., the implications of this approach to care are compelling. It is feasible that putting oneself in the position of women who choose to have the FGC surgery is difficult. Nevertheless being engaged from the perspective, experience, and understanding of the patient, better situates the health practitioner to act on behalf of the patient and to contribute to the welfare of refugee women who choose FGC surgery.

According to the literature, to attend to the welfare of others represents and exemplifies the goal of medicine.¹⁴² Acting in the interest of and for the benefit of others is intimately tied to the objective of medicine. Explained earlier, health professionals are obligated to act in a manner that ensures positive outcomes and that not undermines the patient's autonomous choice. Using Frankena's framework of beneficence supports the adage of acting on behalf of others, particularly refugee women who choose FGC surgeries. It also supports the guidance of health professionals where the scholarship shows that the primary concern of care is non-maleficence rather than beneficence to discern that the aim is to act on behalf of those who are in need of care.

It is interesting and noteworthy to make the connection between acting on behalf of others (beneficence) and observing the desire of the patient through the lens of the patient discussed earlier in this section. Fletcher, Silva and Sorrell for example, explain that when health care professionals view the situation or the request of the patient from their own perspective that the health care practitioner lacks awareness of the patients life narrative, i.e., culture, value and tradition which impedes their ability to garner understanding of the patients meaning of their action or choice.¹⁴³ The responsiveness of the health care professional for the woman choosing FGC honors the ethical principle of respect for autonomy. Emphasizing the viewpoint of the patient, rather the point of view of the health care practitioner facilitates acting on behalf of the

patient.

In contrast however, not considering the point of view of the patient diminishes and devalues the patient.¹⁴⁴ Devaluing of the autonomous choice of the women who choose FGC has consequences for both the health care professional and the patient. Specifically, according to Fletcher, Silva and Sorrell, the implications for devaluing the intention of the patient increases the potential for oppression and violence,¹⁴⁵ two themes often associated with FGC surgery. For the health care practitioner he/she was not successful in acting on behalf of the patient. Furthermore, as a result of not acting on behalf of the patient the quality of life that is afforded to the patient is lost.¹⁴⁶

Acting on behalf of others, namely refugee women who choose FGC includes honoring the person as patient and the autonomous choice of patient. In doing so care is administered in a way that supports the life intention of the patient. When care is afforded in this manner then the voluntary aspect of the choice is respected.

IV. Voluntariness, Non maleficence and FGC

A. Concepts in conflict

Using the bioethical frameworks of non-maleficence and beneficence to examine FGC raises ethical tension between voluntariness, which is part of the structure of autonomous choice, and the principle of non-maleficence. The tension lies in the practical application of non-maleficence to FGC surgeries, namely that the voluntary choice of the patient, and the obligation of non-maleficence for the health practitioner create opposition. For example, when exploring FGC/c through a medical lens, FGC/c is considered an immoral practice that, according to Fran Hosken can result in harm and the need for healthcare.¹⁴⁷ It is however important to include that not all of the research on FGC describes that there are long lasting harmful health consequences

related to FGC surgery.

Fuambai Ahmadu writes concerning the alleged health consequences, “assertions of alleged harmful physical, psychological and sexual effects have more to do with deeply embedded Western cultural assumptions regarding women’s bodies and their sexuality than with the highly disputed health effects on genital operation on African women.”¹⁴⁸ Ahmadu further describes that the mainline examination of FGC is overinflated and unfounded.¹⁴⁹ Highlighting the opposing argument in the debate on the harmful consequences associated with FGC provides a more balanced discourse that is not negative. It also gives way to a different kind of analysis that supports that women are capable and able to make their own decisions regarding FGC, rather than the one that promotes patriarchy as the reason for FGC and that women are seen as passive victims who are engaged in FGC against their will.

Conversely, however, the research explains that women not only support FGC but they preserve, protect and defend the traditional ritual.¹⁵⁰ Since women uphold FGC, and are engaged in the practice, “because they want to”-¹⁵¹voluntariness and the autonomous choice of the women choosing FGC surgery is entirely reasonable to consider. Through the lens of respect for voluntariness, a less negative response is possible. It is the involuntary designation typically assigned to FGC that makes FGC ethically unacceptable. However exploring FGC through the lens of voluntariness creates new possibilities that can facilitate the conflict and imbalance between the health care practitioner and the patient.

Voluntariness investigated in Chapter 3 is a concept salient to the notion of care, particularly when applying the concept to the autonomous decision of those whose healthcare decisions and intentions may not be a normative one. Importantly voluntariness is the third of three conditions necessary for autonomous action. The idea of voluntariness is particularly

relevant to refugee women who will voluntarily undergo the procedure. The voluntary choice of women who choose FGC unearths ethical dilemmas for the health care professional. For example, how does the health practitioner move forward with the choice of women who choose FGC surgery when there are health risks? The importance of working through this ethical dilemma lies in the reality that the conflict raised in the concepts of the voluntary nature of autonomous choice and the idea of non-maleficence for health care practitioners will not dissipate. However, what is helpful is the re-consideration of the application of non-maleficence using Frankena's framework and the guidance of Article 4 in the UNESCO Universal Declaration on Bioethics and Human Rights. In addition, consideration of cultural diversity, a concept examined in Chapter 5 is paramount.

In an effort to continue to grapple with the two bioethical frameworks in conflict, perhaps attention is also given to patient preferences and quality of life. If not continually explored, the ethical concepts in conflict have the potential to serve as barriers to care for refugee women who will choose to undergo FGC. The ongoing attention and the practical application of the concepts in conflict continue to assist in the ongoing effort to work through the question raised in this dissertation-does care imply that the physician/healthcare worker has the obligation to honor the specific health needs of the female circumcised patient in a culture that is in opposition to FGC?

B. Non-maleficence and care

The ethical concept of non-maleficence has been the focus of this chapter. The critical nature of non-maleficence, to do no harm, is highlighted in the FGC scholarship when explaining the assumed health consequences of FGC surgeries. Further investigation of the idea of non-maleficence demonstrates that, without a more balanced and positively situated framework for applying non-maleficence, the intention of the patient is undermined, and other important aspects

are ignored which contribute to the formation of barriers to care. One example of these barriers is that without a strong framework in which to apply non-maleficence then the mainstream application of non-maleficence remains.

For instance, in Frankena's framework of beneficence, the obligation of promoting and doing good is prioritized which can facilitate a positive outcome for the patient. Non-maleficence in Frankena's schema is integrated into the principle of beneficence. Applying non-maleficence to care of women experiencing FGC in this way makes the obligation of beneficence, the primary focus and draws attention to facilitating a positive outcome and assists in removing barriers that can leave the needs of the patient unmet. To be sure, Edmund Pellegrino writes, "the physician's obligation to beneficence is binding."¹⁵² The obligation to beneficence is what facilitates meeting the goals of care and ensures that good care is administered to the patient.

One of the ethical features of care is competence, described earlier in this chapter. Observing non-maleficence through Frankena's framework, which is to promote good first, links competence to care in the following way. First, in promoting good and a positive outcome for the patient, and preventing harm means that the health professional is competent. As it relates to FGC, competence means that the health professional is obligated to be educated about FGC in general and FGC surgeries specifically. The research describes that the education of the health care professional in the West, and particularly in the US where FGC is "happening in New York and Boston"¹⁵³ is deficient and is not sufficient.

The education of health care professionals concerning FGC is critical to the ethical care of women experiencing FGC, and to those women who will choose to undergo the surgery. In addition, education must be balanced and must include the practical application of non-maleficence employed by Frankena, rather than a panic-stricken, overexcited and narrow version

of non-maleficence often found in the FGC scholarship. This type of rendering of non-maleficence to care does not take into account the many nuances of the concept or the “universal moral obligation to do good for and to avoid harm of all humans.”¹⁵⁴ In this way, non-maleficence is applied in practice to the care of refugee women who choose FGC where the goal of medical care is the improvement of quality of life for those who seek and need care.¹⁵⁵

V. Conclusion

The principles of Non-maleficence and Beneficence FGC and Care have considerable and noteworthy implications for the care of women who intend to undergo FGC surgery. One of the promising effects of the principles of non-maleficence and beneficence is the framework offered by Frankena. In Frankena’s schema, non-maleficence is included within the construct of beneficence, which is the moral obligation to “do good” and to work toward a positive outcome that is beneficial for the patient. The approach of this specific framework garners a more balanced and less negative response to FGC. In addition, the focus on beneficence facilitates honoring the autonomous choice and wishes made by the patient, in particular, women refugees who choose FGC surgery. Non-maleficence is then practiced in a way that is more toward helping rather than doing harm. In other words, non-maleficence is focused on promoting help and providing care that fosters positive outcome and change that is beneficial for the well-being of the patient. Beneficence in this framework gives opportunity for ways to reach better outcomes for the patient.

An example of the application of beneficence in the context of FGC is harm reduction, i.e., medicalization. The harm reduction approach and medicalization is an avenue in which patient preferences and life intentions are prioritized and honored. Beneficence applied in this way gives voice to the patient and supports good patient care. The harm reduction approach works to

reduce the alleged health consequences related to FGC surgeries. Medicalization encompasses the human experience, which includes cultural, contextual, and social notions explored in Chapter 5.

Important to discerning what care should be for refugee women choosing FGC surgery, medicalization situates human problems, i.e., FGC health consequences into medical problems which supports the application of the principles beneficence and non-maleficence using Frankena's framework. The research shows that there are benefits to medicalization, namely improvement in health outcomes for women who undergo FGC surgeries and advances in safety while lowering the risks.

The principles of beneficence and non-maleficence are part of the healthcare ethics framework designed to assist in solving dilemmas that arise in healthcare facilitating a standard of care, which prioritizes quality and ethical care for patients. The principle of beneficence obligates the health practitioner to prioritize positive outcomes for her/his patient. Positive outcomes are characterized as the preferences of the patient and the priority of honoring the intentions of the patient.

NOTES

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Chapter 5: Respect for Cultural diversity

I. Understanding Respect for Cultural Diversity

In ethically examining FGC, respect for cultural diversity is a construct worthy of consideration. Through the lens of respect for cultural diversity, FGC is not purely a destructive and off-putting construct, as it is reflected in the literature; rather, the subject is observed from a point of view of relevance and applicability.”¹ This section will focus on fashioning a working definition of cultural diversity and will discuss the reasons and rationales highlighted in the literature for FGC, as the motivation for the practice is often attributed to culture, custom, and tradition. Within the scholarship on FGC, there are robust cross-cultural ethical judgments about the subject that render the question: why should we pay attention to cultural diversity?

Furthermore, respect for cultural diversity raises questions about the right to practice the customs and rituals of tradition, but it is not without moral reflection and examination, particularly when the custom is, for the most part, associated with harm and the un-voluntary and coerced participation. Cultural and moral relativism and the concept of contextual features are explored which allow for taking into account both cultural and religious influences of others in our care.

A. What is cultural diversity?

Most populations today are made up of a variety of races, ethnicities, cultures, languages, customs, and traditions. Countries are no longer homogeneous; rather, they are pluralistic. According to recent estimates, “the world’s 184 independent states contain over 600 living languages, and 500 ethnic groups”² This melting pot of numerous cultures, ethnicities, races, and religions have implications for the U.S. cultural context. One implication is that in the pluralism present in the U.S requires that health professionals, practitioners and students in health professions the ability to communicate, understand and respect the diversity of cultures.³ Paying

attention to the complexities of the subject of respect for cultural diversity requires an interdisciplinary approach that can give consideration to the dialectics between the culture of the individual and the culture in which the individual, namely refugee women experiencing FGC, resides. Social context and culture are an undeniable prerequisite in considering what morality recommends in providing care. Women from FGC communities, who live in the United States, face very distressing adjustments. An illustration of the adjustment is moving from a community where FGC is a social cultural tradition to living in an environment where the tradition is deemed taboo and even illegal for females under the age of eighteen to undergo. One scholar notes, there is an “eruption when people from societies practicing female circumcision /female genital mutilation settle in other parts of the world and bring their rites with them.”⁴ In the U.S., there is unfamiliarity about the custom of FGC, and therefore, if there is going to be a model of care that is sufficient for women who experience FGC, it must include respect for cultural diversity.

There is a cadre of meanings, descriptions, and definitions of what constitutes culture and cultural diversity. For example, some of the literature on cultural diversity describes cultural diversity as learned and transmitted values, beliefs, and practices of a particular group of people.⁵ However a more expansive framework is employed in examining and applying respect for cultural diversity in the context of care to refugee women who choose to undergo FGC surgery. According to the *Universal Declaration on Cultural Diversity*, “ the defense of cultural diversity is an ethical imperative, inseparable from respect for human dignity...culture should be regarded as a set of distinctive spiritual, material, intellectual and emotional features of society or a social group and encompasses lifestyles, ways of living together, value systems, traditions and beliefs.”⁶ Culture, it is said, is the lens with which individuals see the world, and the lens extends to health and healthcare.⁷ Paying attention to the multiplicities of cultures and respect for the

diversity requires an interdisciplinary approach particularly when the values, traditions, beliefs and lifestyles are different between the health care practitioner and the patient. An example of how cultural diversity impacts healthcare is choices women make concerning care. Women who choose FGC do so, based on their customs, values and beliefs embedded in society and a culture to which they belong. In Ethiopia for instance, circumcised female genitalia are considered normal just as males who are circumcised are considered normal to Americans.⁸ Refugee women who settle in the U.S. bring their customs with them and transmit cultural customs to their children particularly daughters who may choose to honor the cultural tradition of FGC surgery.⁹ In this context, respect for cultural diversity becomes one of the ethical lens and frameworks by which FGC for women who are no longer minors is examined and applied.

In health care ethics, respect for cultural diversity is associated with the care of the patient. Respect for cultural diversity is also one of the features of global bioethics. Within the framework of the patient-health practitioner relationship, both the health practitioner and the patient bring to the relationship duties and responsibilities to the larger world in which their relationship takes place.¹⁰ In the context of care, the contextual features of their culture influence the preferences of the patient, especially women whose life intention is to undergo FGC surgery. These aspects of culture include lifestyle, values, beliefs and traditions. As it relates to the scholarship, in the case of FGC, the health practitioner observes the contextual features of the patient in conflict not only with his/her culture, but also their commitment to the patient.¹¹ The scholarship describes that some health practitioners disagree that contextual features, i.e., cultural considerations of the patient are important in determining ethical decisions about care, namely to consider the care of women experiencing FGC. However, scholars argue that the beliefs and practices of the patients cultural orientation that are culturally different than the

health practitioner's is "real and in varying degrees obligatory"¹² for the patient. Therefore it is incumbent upon the health practitioner to respect the cultural diversity of the patient and to consider cultural diversity in determining care for women experiencing FGC. Health practitioners have a moral obligation to do so.¹³ Women who have chosen to undergo FGC surgery do so based on their experiences, ideals, values, and their beliefs. Respect for cultural diversity that includes an understanding of the beliefs and ideals of the patient and how they guide thinking, actions, decisions,¹⁴ are vital and necessary for good patient care. Not only are these cultural characteristics integral to care, they frame how individuals view health and the need for care.¹⁵

In examining the literature to secure a definition of cultural diversity the term multicultural or multiculturalism is observed. It is important to highlight the difference in the two terms although at times they are used interchangeably. Cultural diversity, as explained earlier in this section, is a distinct set of features that is shared by a group of people. These features are known as custom and traditions and they impact the patient's perspective on health, particularly refugee women who choose FGC. An example of this shared view on health is FGC surgeries, where women, particularly women in Africa do not share the same unbalanced and hysterical responses to the cultural custom.¹⁶

Multiculturalism, on the other hand, denotes several cultural or ethnic groups within a society. Multiculturalism incorporates ideas, beliefs, or people from many different countries and cultural backgrounds and encourages interest in many cultures within a society rather than in only a mainstream or dominant culture.¹⁷ Further, multiculturalism is an expression that describes a framework that supports responding to cultural diversity. For example, Radka Neumannova writes that the "multiculturalist perspective [multiculturalism] responds to the cultural diversity

brought in by immigrants as a consequence of their migration.”¹⁸ Alternatively, Kymlicka notes that ‘polyethnic’ better describes where “cultural diversity arise from individual and familial immigration.”¹⁹ Neumannova further explains that multiculturalism is a model of defense of cultural rights and has its underpinnings in the universal rights of an individual.

It is in the diversity of culture nestled in the dominant cultural construct that makes respect for cultural diversity a strong framework for discerning what the care is for women who choose FGC. Paying close attention and giving priority to respect for cultural diversity in the context of care requires sensitivity to the differences transmitted by individuals from various cultures, which influence decisions concerning care. It is in the framework of cultural sensitivity that positive and beneficial outcomes are realized.

B. Cultural Sensitivity

Cultural sensitivity refers to an awareness of different cultures; each culture is different.²⁰

Differences and similarities have an effect on values and behavior. Culture is a dominant feature in the FGC discourse and many of the reasons for the custom are embedded in culture.

Understanding the cultural context of women who experience FGC and those who will choose to undergo the procedure assists in garnering respect for cultural diversity. When refugee women come to the United States, now a multiethnic society, they bring their health care needs.

Sensitivity to values, beliefs, and behavior and applying understanding can improve “communication and care.”²¹

One important feature concerning culture, especially in the context of FGC, is that there is diversity within cultures. An example of the diversity of cultural practices is the different types of FGC surgeries that take place within cultural groups. According to Toubia and Izett, in Somalia where the rate of FGC is 98 percent, approximately 80 percent of the surgeries are

infibulations, the most invasive of the FGC intervention.²² The remainder of the FGC operations performed is clitoridectomies, a less invasive FGC procedure.²³ These cultural difference between groups within a culture is an illustration for why assumptions cannot be made in caring for women who are experiencing FGC and why sensitivity must be employed.

Cultural sensitivity is the awareness of people from other cultures and includes thoughtfulness and tolerance without judgment about how the values, beliefs, and customs of cultures, different from the dominant culture, impact how others live and make decisions that affect their lives.²⁴ The Committee on Health Care for Underserved Women defines cultural sensitivity in the following way- it is the “knowledge and interpersonal skills that allow health providers to understand, appreciate, and work with individuals from cultures other than their own and involves acceptance of cultural differences, and self-awareness.”²⁵ Because culture includes many aspects of an individuals life, i.e., faith, gender, ethnicity, race, socioeconomic status²⁶, the health practitioner, particularly when working with women who choose FGC, a traditional cultural practice that is at odds with the U.S. medicine, must employ strategies that allow for care, namely cultural sensitivity. Cultural sensitivity is one vehicle that facilitates needed communication between the health professional and the patient who is in need of care.

Many cultural groups live in the U.S, contributing to the pluralistic ethos rather than the homogeneous one. In fact, “the world in which we live is by nature pluralistic.”²⁷ This melting pot, if you will, of individuals and groups of people who have a plurality of religions, ethnic and racial backgrounds, political views, and cultural traditions and practices live together, requiring sensitivity and acceptance. The pluralistic environment is considered valuable and promises living together in a way that brings respect and a shared common understanding.²⁸ Related pluralistic environment is that the values and the differences experienced and shared by a

pluralistic and culturally diverse society are equal and unable to be organized and arranged by a hierarchy or judged as it relates to an absolute standard.²⁹ In other words, the degree of value placed on all customs and beliefs etc. are the same, and the cultural features of one group are not more important or held in higher esteem than another.

On the other hand, however, the views, beliefs, and values of one culture may be different than those of another- for example the beliefs and values of the cultural tradition of a women who life intention is FGC versus the health practitioner who does not understand these values and beliefs which are in conflict. There are limitations to diversity and plurality. One of the limits is that cultures are unable to exist together in harmony. What I mean by this is that at times differences cause conflict that seems unable to be resolved. Often at the root of the disagreements between diverse cultures is that one culture believes that their values, beliefs and practices are right while those that are different are wrong, namely ethnocentrism. An example of the limits of diversity can be found in the context of diverse religions. The incompatibility of cultures causes opposition, misunderstanding, and discord.³⁰ The discord often experienced in differing cultures is that one culture believes that their way of doing things is the right way. This viewpoint is also known as ethnocentrism. It can also be defined as judging another's culture specifically by the values and standards of one's own culture or ethic group. Specifically there is judgment related to language, behavior, customs, religion, and behavior. Interestingly, the judgment concerning customs can be observed in the debate over FGC. In as much as it relates to western ethnocentric response and dialogue of FGC surgeries, Lane and Rubinstein make the following observation. While western feminist writers are credited with much of what is known about FGC, African and Arab women have found the majority of Western narrative degrading and reflective of ethnocentric and Eurocentric preoccupations with sexual functioning and other

concerns valued in the Western culture and society.³¹ Further, the manner in which western writers characterized the culture, women, men and families who practice FGC was seen as, “intolerant and insensitive.”³² An example of cultural insensitivity is the use of term “mutilation” first coined by Hosken and later adopted by the World Health Organization to describe the cultural custom.³³

In exploring the scholarship on FGC surgeries, other offensive and insensitive terms are observed to describe to traditional cultural custom. Terms used to characterize the traditional practice include but are not limited to torture, barbarism, cruelty, savagery, and ritual torturous abuse.³⁴ Certainly the hurtful and judgmental language used to describe FGC polarizes the discussion. The polarization fosters the mainstream negative viewpoint of FGC and imposes labels on people who live in FGC communities. It is in this light that the ethnocentric construct that describes the superiority of one's own ethnic group or culture, is damaging. The redress needed includes the cultural sensitivity framework, which includes tolerance, acceptance, communication, mutual understanding, and respect for cultural diversity.

Since we have established that there is no absolute standard as it relates to cultural diversity and plurality, it is in this light that cultural sensitivity as it relates to care is a necessary framework. Cultural sensitivity and respect for cultural diversity is necessary for those women who choose a cultural tradition practice that is incompatible with the dominant cultural sensibilities of, for example the U.S and who are in need of care.

Important to parsing out cultural sensitivity, in order that it may be applied to care for women who undergo FGC surgeries, is the idea of responsiveness explored in chapter four of this dissertation. As a way of continuing to better articulate cultural competence explored in chapter seven of this dissertation, Betancourt et al., offers the use of term responsiveness among others to

encapsulate the meaning of cultural competence and sensitively.³⁵ It is important here to note that the use of the terms cultural sensitivity and cultural competence are used interchangeably.³⁶ Responsiveness is highlighted to make the connection to cultural sensitivity and to care, which is a construct needed in determining what care should be for refugee women who choose to undergo FGC.

Responsiveness is related to the communication with and mutual understanding of the patient whose cultural context is different from that of the health professional. According to Joan Tronto, responsiveness is not putting ourselves in the position of others rather it is considering the others position from the place where it is expressed,³⁷ namely from the position and the cultural context women who choose to undergo FGC surgery and in need of care. In this way the health professional is involved from the perspective of the patient and not from the assumption that the patient's viewpoint is the same.³⁸ The position and viewpoint of others is the cultural context in which the patient views and lives in the world. Understanding the cultural context of the patient who is choosing to undergo FGC surgery can improve communication and care.³⁹ The cultural sensitivity framework and approach assists in advancing the occurrence of cultural connectedness between the health practitioner and the patient who is in need of care.⁴⁰

Respect for the diversity and plurality of culture is an integral part of what care should be for refugee women who chose FGC surgeries. Respect for cultural diversity is critical even when the values, beliefs, customs, and traditions are in conflict with the health profession- especially when it comes to what constitutes quality of life for the patient, a topic investigated in chapter four. The cultural sensitivity framework allows for the garnering of mutual understanding and appreciation for other, which facilitates the application of cultural diversity, particularly in fostering care for women who choose FGC surgeries.

II. Applying respect for cultural diversity to refugee women choosing FGC

In reflecting on what the care should be for women who choose FGC surgeries, the concept of respect for cultural diversity is a significant consideration. Its significance lies in both the culturally embedded nature of FGC surgeries and its continued cultural persistence despite ongoing attempts to eradicate the traditional cultural custom.⁴¹ However, there are those who defend the practice and draw support for their position, for example the right to autonomous choice, respect for a person's particular cultural and individual identity to cultural traditions and practices. Those who defend FGC do so from the perspective of protection for the rights of minority cultures.⁴² Supporting the right to autonomous choice and respecting the particular cultural identities, particularly for women who choose to undergo FGC surgeries in cultural environments that do not share the cultural tradition, is at the heart of the bioethical construct—both the western construct and the global one.⁴³ These bioethical frameworks facilitate care that allows for the patient's perspective and life intentions to be primary and for the outcome to be one that facilitates medical treatment that improves the quality of life for women who are in need of care.⁴⁴ Respecting cultural diversity takes into account the plurality of values, beliefs, customs, and traditions of those who seek care, particularly women who experience FGC surgeries.

The cultural landscape in the U.S. is changing. In so far as applying respect for cultural diversity, the principle denotes that the framework and ideology of bioethics are applicable and necessary for all people regardless of the culture the patient represents.⁴⁵ As a result of the changing landscape in the US there is a pluralistic environment where cultural groups have traditions and customs that are often unfamiliar to health practitioners. Since the goal of medical care is to improve the quality of life for patients by having positive outcomes for those who seek

care, there is a need for the practical application of respect for cultural diversity. What I mean by practical application is the need for a “hands on” approach for respect for cultural diversity in caring for women who choose FGC. In reflecting on how respect for cultural diversity is practiced consideration for the use of an “emic perspective”⁴⁶ is useful.

Because of the intricacy of FGC, the investigation of what care should be for women who choose FGC is an interdisciplinary endeavor. The terms “emic” and “etic” are used in field of anthropology and refer to viewpoint and perspectives.⁴⁷ The emic perspectives refer to the indigenous views of their own behavior, or the “insider viewpoint.”⁴⁸ On the other hand, the etic perspectives are the viewpoints of those who are outsiders.⁴⁹ Interestingly, there is a correlation of the emic and etic perspectives to FGC debate. In the FGC scholarship it is known as the insider/outsider conflict. According to Mary Nyangweso Wangila, there are a number of scholars who have contributed to the FGC scholarship, however these scholars come from cultural contexts where the traditional custom is not practiced or they themselves have not experience the procedure.⁵⁰ With regard to the FGC debate, it is apparent that western writers, particularly those who identify as western feminist writers, do so with what appears to be a lack of sensitivity and respect for difference and with an ethnocentric underpinning. Ethnocentric underpinnings mean that anything other, for instance any practice or custom other than western ideologies, is wrong and unnatural. In other words, the judgment inferred seems superior and without balance. To this end, Wangila explains that outsiders have been criticized for interfering in the internal affairs of communities who circumcise and that their critique on FGC is based on the assumption that “western culture is a dominating culture self-appointed to be the barometer of morality and ethical standard.”⁵¹

Likewise Fuambai Ahmadu, an African feminist writes concerning the “etic” viewpoint or

the outsider perspective is the assertions often found on the harmful affects of FGC are often alleged and are no more than misrepresentations.⁵² Ahmadu further adds that the aversion of some western writers to FGC has more to do with the deeply imbedded western cultural assumption regarding women's bodies and their sexuality than with the "disputable health effects of genital operations of African women."⁵³ One example of the hypersensitivity regarding sexuality in general and African women's sexuality specifically is the focus on what is considered a "natural" vagina. The term natural seems subjective and can be defined according to what is deemed conventional or acceptable to the culture. The term natural needs further definition not attended too here.

However the word natural/nature denotes existing because of or caused by nature. A sentiment often articulated in the FGC debate is that the cultural custom is unnatural. Not only is circumcision a custom that defies nature but the cultural tradition also disturbs the natural appearance of the vagina. What is important to note here is that some cultures believe that the female clitoris can and will grow to mirror the male penis,⁵⁴ and the surgery is done because having a clitoris that a penis is unnatural. According to Ahmadu the concept of "nature" and "culture" in Africa and particularly within the Kono culture, the meanings differ significantly from western ideas of the terms and it is the insider or the "emic" understandings of nature and culture that compels both female and male circumcision."⁵⁵ The relationship that different cultures have with nature is not only diverse, it is critical to care.

The United States culture, for instance, believes that people can control nature. Geri-Ann Galanti argues that this way of thinking about nature also relates to the culture of health care in the US. She explains that the view of health care in the U.S. is that the body is a machine, if the heart for instance does not work, turn it over to the mechanic (health care practitioners), and

replace it.⁵⁶ The “emic” perspective regarding the U.S. culture of healthcare is helpful. Its usefulness lies in the fact that not all cultures have this belief in this way, and the difference, particularly in the context of care, can cause dismay on the part of the health professional. Conversely, concerning nature as it relates to the “emic” perspective of nature and the body, Asian and Native American cultures see human beings as part of the nature; therefore, when these cultures experience illness they will look to the earth treatment.⁵⁷ It is in the context of culture, particularly FGC communities that an “emic” perspective can be applied.

It is important to note that the “etic” or the outsider perspective is also a valuable consideration. Because the two viewpoints, “emic and etic” represent differences according to Galanti, being familiar with both perspectives, the viewpoint of the health professional and the patient affords a more comprehensive picture, a necessity for health practitioners when caring for patients,⁵⁸ particularly women who experience FGC surgeries who are from different cultures. In this way the health professional can attempt to comprehend and appreciate the perspective of the patient as it relates to the choices made and the life intention of the patient.⁵⁹ Recognizing and understanding choices and life intentions from the “emic” perspective of different cultures facilitates respect for cultural diversity in a way that values the traditions and beliefs of others. Understanding the “etic” perspective of that the health professional brings may assist in dismantling biases that can facilitate the dishonor of patient’s autonomous choice and the disrespect for cultural diversity which can lead to cultural marginalization. What I mean by cultural marginalization is that the patient, namely women who choose FGC and are need of care are deemed insignificant due to their cultural traditions, customs and practices which place them in a seemingly powerless position within US health care culture. This place of cultural marginalization impedes the care of those who are from different cultural contexts, particularly

women who experience FGC, and it inhibits the “fundamental goal of medical care; the improvement in the patient’s quality of life.”⁶⁰ Without the integration and application of respect for cultural diversity, which allows for mutual understanding of the cultural significance of FGC, care is not realized.

A. Cultural significance; Rationales and Justifications for FGC

There is a cultural significance to FGC. The importance is related to the various reasons and justifications for the procedure and is connected to value. This section will examine and consider the justifications in detail, and will elaborate on the religious influences and the influence of tradition, as much of the influence exists due to religious beliefs and traditional values. Rosemarie Skaine illustrates various reasons and justifications for the FGC procedure. For instance she explains that FGC is comprised of four categories: socio-cultural, hygienic/aesthetic, spiritual/religious and psychosexual.⁶¹ Rahman and Toubia explain that the reasons for FGC are complex.⁶² The complexities related to the rationales lie in the intimately woven beliefs and values of the community.

In fact, Rahman and Toubia describe that the justifications and reasons for FGC “depend upon an entire belief system, not a single factor.”⁶³ Since the traditional practice is firmly established within the context of culture, ethnicity, and geographic location, the reason and rationales for the practice are as diverse as the places where the custom is practiced. An example of the variation in practice due to geographic location and reasons for FGC is observed when examining the prevalence of the traditional practice in African countries. In an analysis of the prevalence and reasons for FGC surgeries in geographic locations in Africa, Toubia and Izett found that the estimated prevalence of FGC and reasons for the surgery are diverse. For example, Toubia and Izett explain that in Mali there is a 94% prevalence of the practice, except in the

regions of Gao and Tombouktou. Types I and II FGC surgeries are predominant.⁶⁴

Interestingly, FGC is practiced by all religious groups ranging from 85% Christian and 94% Muslim. FGC is common across all ethnic groups. However, in the Sudan, while the prevalence is estimated at 89% the research shows that 89% of the women who were married had been circumcised.⁶⁵ There are diverse reasons and rationales to be investigated in more detail below. Nevertheless, what is a persistent theme is marriageability and religious tradition. Important to the discussion on reasons and rationales for FGC are chastity and fidelity. Chastity and fidelity is referred to in the FGC scholarship and are included in the reference to marriage as a rationale for undergoing FGC.⁶⁶ In a study conducted by the World Health Organization (WHO) they concluded that the prevalence of FGC could vary substantially within the same country.⁶⁷ For instance, reports of FGC are common in the southern regions of Nigeria but are substantially less frequent in its northern regions. An important finding in the report reveals that educational level of women engaged in FGC, wealth, and religion are indicators of the increased rates of FGC.⁶⁸ Religion is one of the major influences attributed to FGC and is fully examined in chapter one of this dissertation. It is credited to the origins of the both male and female circumcision and the transmission, prevalence and persistence of FGC. Religious beliefs are also one of the main influences that shape social culture and social norms. It is connected to social conformity and certainly to ones value system. When linking FGC to religion, one scholar describes “religion is one of the reasons consistently given for performing the practice but is also a strategy for addressing the issue.”⁶⁹ In a study focused on why women practice female circumcision, the results highlighted that 90% of women report that religion influences their decision for engaging in the practice.⁷⁰ In considering the cultural significance of the traditional practice, it is important to note that FGC is embraced as a religious ritual surgery.⁷¹ The FGC

surgery meets a religious requirement often juxtaposed to the symbolism of male circumcision in Judaism.

As it relates to religious beliefs, spiritual practices, and health care Geri-Ann Galanti explains that while religion is not a subject of conversation in hospitals; the customs, traditions, and beliefs of patients are. These aspects of religion are often sources of conflict, disagreement, and misunderstanding;⁷² however, they play a fundamental role in how patients make decisions about care and about quality of life. Since religion is one of the most common themes that typically justify the cultural significance of FGC, health practitioners would do well to gain an understanding of the religious influences. For example religion is connected to cultural heritage which influences religious beliefs and practices connected to of FGC, much like the cultural heritage linked to the practices of Jehovah's Witness. Being aware of religious influences assists in the effort to have a culturally sensitive and culturally competent approach to care. In addition, recognizing the diversity of reasons and rationales and the cultural significance of them, instead of assuming that there is just one reason, can serve to have a better understanding of the patient and in discerning what the care should be for women who choose FGC surgery and are in need of care.

i. Aesthetics/ hygiene

The aesthetic rationale concerning FGC surgeries dates back to antiquity.⁷³ The aesthetic reason for FGC surgeries is associated with a belief system in parts of Africa that holds that the clitoris grows to the size of a male organ. As a result of this seemingly unnatural occurrence some women in Africa describe their genitalia as ugly and their genital area was similar to that of men. A number of authors writing about FGC in ancient times explained FGC surgeries were strictly an aesthetic measure used to either correct or improve the appearance of the female

genitalia.⁷⁴ It is reported that having genital modification (FGC) not only corrected the enlarged genitalia, the surgery also beautifies the genitalia to look more feminine. The corrective surgery explains Gollaher, was to correct where the labia minora seemed unnaturally large.⁷⁵ Important to the cultural significance of aesthetics to FGC is that for much of history women were thought to have the same genitalia as men. According to Gollaher, the only real difference between women and men was that the genitalia of women, namely the clitoris, was on the inside of their body, while the genitals of men, that is the penis were on outside.⁷⁶ Having noted the historical suggestions regarding the claimed similarities between male and female genitalia, it seems that the aesthetics rationale for FGC surgeries was not only cosmetic but also medical. According to Gollaher the “deformities of the female organs were caused by the sweltering and hot climate which rendered circumcision medically necessary.”⁷⁷ In fact, the historical account for the rationale of medically necessary circumcision dates back to the sixteenth century.⁷⁸ Important to the historical features of aesthetics and its relationship to the medical necessity for circumcision is the association of aesthetics to religion.

In the sixteenth century, Catholic missionaries in Ethiopia worked to prohibit FGC. Because marriage was considered customary, difficulty emerged when uncircumcised Christian women were not able to get married and were considered unmarriageable,⁷⁹ a theme investigated later in this dissertation. However, provisions such as medical intervention were made. David Gollaher describes that a surgeon sent from Rome determined that the deformity of the clitoris of Ethiopian women was abnormal “provoking a natural aversion in men and thus appropriate objects of surgical revision.”⁸⁰

In facilitating the FGC surgery for Christian women, women were made desirable for marriage and connecting the practice to marriage and religion.

Specific to the aspect of aesthetics and pertinent to the cultural significance of FGC is the gender identification issue apparent in many cultures. Gender identity especially in FGC communities is one reason for circumcision. The rationale is focused on the “protruding clitoris and other tissues.”⁸¹ FGC is practiced to absolutely distinguish the sex of a person,⁸² contributing to the pervasiveness of the practice. For example, Marie Bassili Assaad describes there is a belief within Egyptian culture which has been transmitted to other parts of Africa that “a boy is ‘female’ because of his foreskin; and a girl is ‘male’ by virtue of her clitoris.”⁸³ Having this insider or “emic” perspective of this aspect of the culture helps in seeing why there may be the necessity for FGC surgery, from the perspective of the patient. Importantly, since marriage is a valued cultural standard and the aim is the removal of male-like feminine organ, it critical if marriage is to be achieved, a subject explored later in this dissertation. The clitoris and labia, in cultural contexts where they are considered male parts, must be removed lest they produce ambiguity.⁸⁴ The circumcision would also apply to males. For males the foreskin (considered female) must be removed before the stage of manhood to disregard any uncertainty about gender.⁸⁵

In considering gender and aesthetics, FGC surgeries in Africa, are viewed by insiders (emic) as aesthetic enhancements. However, it is important to say that there is human desire across all cultures to shape and decorate the body to accomplish a culture’s aesthetic ideals. Examples of these aesthetics are ear piercing, body tattoos, and other forms of surgical body modifications and enhancements. This desire is what is at work in the case of FGC surgeries.⁸⁶ The FGC surgery enhancement is aimed at making the genitals more “attractive-smooth and clean.”⁸⁷ It is important to note that FGC communities who support and promote type IV, i.e., infibulation or Pharaohnic circumcision, find the smooth infibulated vulva highly feminine and

aesthetically pleasing.⁸⁸ Mentioned earlier, not only is the FGC surgery associated with enhancement, it is also related to hygiene and purity. The relationship of hygiene and purity to FGC is due to the belief that the larger the clitoris the “dirtier and uglier it is. The state of being uncircumcised was termed dirty and had to be washed away.”⁸⁹ It is important to note here that both purity/hygienics and aesthetics are reasons attributed historically to circumcision. In the historical literature on the FGC, hygienics is associated with the idea of purity, a notion also embedded in the early Egyptian culture.⁹⁰ In some FGC communities, for example in northern Sudan hygienics and purity are named as primary reasons for circumcision of both males and female. Bacterial or fungal infection is also considered important to the hygienic reasons for FGC. Some FGC communities believe that circumcision is the one way of making the vagina much cleaner.

While most women agree that the procedure is painful, especially when there is no anesthesia, they embrace circumcision as a rite of passage to being a woman. Circumcision then serves as a way for women to embrace their femininity and increase marriageability while beautifying the genitalia. Many women who have had FGC surgeries view the procedure as a “cosmetic beautification” that improves the appearance of the human female body.⁹¹

ii. Prevention of infidelity

At the time of marriage in FGC communities, virginity is of critical importance. In addition to virginity at marriage, the prevention of infidelity, i.e., marital fidelity is fundamental in FGC cultural contexts.⁹² Prevention of infidelity is a theme often observed in the scholarship on FGC. The idea of virginity at marriage is not only an ideology embraced in FGC communities, it is also an ideal in the cultural context of the United States. While some scholars admit that virginity at marriage is less of a custom as it once was, “virginity remain symbolic by virtue of the white

wedding dress and veil.”⁹³ In this regard the ideal of marriage is a shared custom, both in FGC communities and in non- FGC environments. In the U.S. cultural context, marriage denotes stability. Marriage and virginity at marriage is often part of a religious tradition both in FGC communities and in the U.S.

The importance of virginity, especially in Islamic FGC communities such as the Sudan, virginity is linked to Islamic prohibitions on sex outside of marriage.⁹⁴ The same can be said for some protestant religions and the Catholic tradition. Observance and faithfulness to the cultural custom of virginity at marriage if you will, is part of a persons morality. In other words, faithfulness to tradition depends upon the values held by an individual, which assist her/him in discerning behavior that is characterized as right and wrong, or actions that are good or bad. Concerning the vow of virginity at marriage, especially in FGC communities, Ellen Gruenberg explains, “adherence to virginity is considered both a social requirement and a religious obligation.”⁹⁵ According to Gerry Mackie, FGC is necessary for proper marriage. In this way, there is proof of fidelity and prevention of infidelity before marriage. What is meant by infidelity before marriage is the belief in women not having sex before marriage. Virginity at marriage and fidelity in marriage are an important place of honor and decency- to maintain it, one must have decency with respect to sexual behavior.⁹⁶

In an effort to maintain the decency and honor, FGC ensures that women (and young girls) have not had sexual relations before marriage. Premarital chastity is undoubtedly linked to FGC. It is important to mention here that the idea of virginity at marriage and prevention of infidelity as it relates to FGC can be proven most often by undergoing infibulation or Pharaonic intervention. The reason virginity can be proven is that the infibulated vulva creates scar tissue sometimes referred to an “ordinary” barrier making it nearly impossible to penetrate.⁹⁷ In

addition to the barrier created by scar tissue, the removal of the clitoris allegedly reduces sexual desire. The reduction of sexual desire will simply help to keep women from having sex prior to getting marriage. If women in FGC communities are not having premarital sex then they are less likely to have illegitimate children.⁹⁸ In addition, not only does the literature note that FGC promotes fidelity in marriage, “infibulation is more likely to make sex less appealing and therefore less of a temptation”⁹⁹ to women to go outside of their marriage. In some FGC communities proof of virginity is celebrated. However in Western Sudan, proof of virginity is customary.¹⁰⁰ Proof of virginity is by way of a spotted cloth on the bride and grooms wedding night. The show of cloth spotted with blood symbolizes the bride’s virginity and success of the family to protect the virginity of the daughter via FGC.¹⁰¹ Having done so, the bridegroom pays the mother with cattle or money, adding to the family’s economic success.

iii. Economics

One economic feature of FGC is linked to marriageability (marriage). While there is not an abundance of research related specifically to economics and FGC, economics is highlighted as justification and sometimes is motivation for FGC and therefore should be mentioned. The motivation for FGC is linked to the strong cultural value of marriage.

As mentioned in the earlier section on aesthetics, marriage is one primary rationale for FGC surgery, although in the literature marriage is not specially mentioned. Rather it is implicit in the discussions on custom and tradition, social pressure and religion.¹⁰²

For example, as it relates to custom and tradition, FGC is performed as a rite of passage. The rite of passage marks the transition from childhood to adulthood. In fact, in FGC communities a girl is not able to become a mature adult unless her clitoris is removed.¹⁰³ It is the process of entering in to womanhood. According to Anika Rahman and Nahid Toubia, during this time of

transition from childhood to becoming a woman, the girl is said to be equipped with the abilities to handle marriage, a husband and children.¹⁰⁴ The process of becoming a woman, thus being able to marry, is incredibly important economically to women and to families in Africa in general and in FGC communities specifically.

The economic security for women is not only linked to marriage, but it also intimately connected to reproduction and to social status.¹⁰⁵ Therefore the role of family plays a tremendous part for why FGC surgeries are performed. The economic landscape in Africa, and particularly in the Sudan strongly favors men. For example, Ellen Gruenbaum explains that livestock ownership is in the hands of men.¹⁰⁶ FGC enables the marriage of women therefore facilitating economic security. The significant economic security is in her role as a wife and as a mother and in the use of the animals.¹⁰⁷ Further, for women who have no education, there are very few opportunities for employment. Loretta Kopelman writes concerning economics and FGC, that in order for women to survive economically, women in FGC communities must marry. Furthermore, women are not “acceptable marriage partners unless they have undergone the ritual surgery.”¹⁰⁸ Olayinka Koso-Thomas writes, concerning marriage and FGC, that men from FGC communities insist that in order for women to be acceptable wives they must be circumcised.¹⁰⁹ This is true even for women who have an education and are able to find prestigious employment, i.e., teachers, according to Gruenbaum, “employment is no guarantee of social respect or long-term economic security.”¹¹⁰ There is no other way to provide stable economic security or achieve a place of respect in society but to have a family.

There is a second aspect of the economics concerning FGC that is interesting to note. That is the importance of FGC to older women who are for performing rituals.¹¹¹ Women performing FGC surgeries are often referred to as midwives or elders. Scholars write about FGC that the

custom is a practice controlled by women. There are women who are proponents and supporters of the practice. Because FGC is often a ritual ceremony denoting womanhood, midwives are often the one who typically perform the surgery while other women in the community are present. The midwife also provides a certificate certifying that the circumcision was completed.¹¹² As mentioned in the section about economic security and respectability, the midwife or as she is sometimes referred too, the circumciser/matron makes her living by performing FGC surgeries. It is noteworthy as previously mentioned, FGC, is controlled by women. In other words, mothers, grandmothers, and other female kin dominate FGC.¹¹³ Recognizing that in many African societies FGC is a prerequisite for marriage and children are vital aspects of the roles of women and the economic survival helps to contextualize FGC in a larger social setting.

iv. Social status

The idea of social status is one of the dominant features concerning the cultural significance of FGC surgeries. What is meant by social status is the amount of honor or prestige attached to an individual's position in society. Status implies the position one holds in a social group, namely a community. An illustration of status within FGC communities is that, in certain situations, FGC is an important symbolic marker that identifies women who belong to privileged ethnic groups.¹¹⁴ In addition, FGC is used ideologically to exclude lower status groups who seek cultural assimilation necessary for upward mobility by adopting the cultural tradition.¹¹⁵ Status and position are important as they determine what function a person will have within a group. Tyler refers to social position as the location of the individual within the group – their place in the social network of reciprocal obligations and privileges, duties, and rights.¹¹⁶ Social status is embedded in the cultural context of FGC communities. FGC is a cultural custom, related to

marriage, and it contributes to the cultural significance of social status. In fact FGC is symbolic of a change in the initiated person's social position.¹¹⁷ Gaining an understanding of the social meanings of customs and traditions helps in appreciating the cultural practices of others, namely FGC. Garnering a different perspective by gaining an understanding assists to give insight into belief systems on which FGC is based or supported.¹¹⁸ To develop an “emic” perspective rather than an “etic” viewpoint regarding the cultural significance of FGC helps the health practitioner apply respect for cultural diversity to the care relationship. Furthermore, being able to grasp an emic perspective assists the health professional in realizing and appreciating the influence of social status particularly in the FGC cultural context. In addition the emic viewpoint facilitates awareness about how social status precipitates FGC surgeries.

According to the World Bank, women make up more than half of the population in world.¹¹⁹ However, the status of women in most societies and cultures is lower than that of men.¹²⁰ This is most likely because of the particular attributes, roles and responsibilities related to gender imposed by society. Mary Nyangweso Wangila describes that the low status of women is due to social factors that include patriarchy, sexism, cultural stereotypes, education and illiteracy, and religion.¹²¹ Much of the literature on FGC attributes the practice and the persistent presence of the practice to patriarchal structures and male dominance.¹²² On the other hand, L. Amede Obiora explains that the viewpoint that perceives the patriarchy paradigm that men exert complete and total dominance over societal life can obscure the variety of ways in which men and women are intricately interwoven together as social units and institutions that cut across gender lines in all areas of social life.¹²³

In light of the discussion on marriage highlighted in an earlier section of this chapter, it isn't problematic to appreciate the priority and importance of marriage for women in FGC

communities. It is particularly less difficult to see how the idea of ritual cutting plays a major role in the social status of women, especially when it appears that the only thing that guarantees social status or social respect for women is marriage. Certainly social status is critical to social integration and to honor the value of family. Women who are uncircumcised risk becoming outcasts in their community and in society.¹²⁴ Women find their social indispensability not as partners, rather, they find it in their ability to reproduce, i.e., give birth to children and namely sons.¹²⁵ In this way, women are socially important people. They have status and position. The role they play is vital to family and cultural heritage and to having an heir, mainly a son to pass the family wealth if any and to pass down the family ancestry. In fact, women are “cofounders of lineages,”¹²⁶ which carries social respect, social status, and a place of honor in the community. Taking into account the association of the reproductive nature of women to social status and honor in the community, the idea of social status is embedded in the cultural significance of FGC.

The idea of social status is connected to the religious beliefs of all cultures. As it relates to the cultural significance of FGC, the influence of religion is especially linked to cultures that embrace FGC. It is important to note however that there are arguments that reflect both sides of the debate, namely that FGC is linked to religious beliefs and that FGC is not associated with religious tradition. For instance, Rahman and Toubia argue that FGC is a cultural practice and not a religious one.¹²⁷ They assert that FGC predates the arrival of religious traditions, particularly Christianity and Islam in Africa.

Conversely, however, other scholars argue that religion is a reason for the practice of FGC and that women and men alike embrace this belief. FGC is practiced in religious traditions that include Judaism, Christianity, Islam, and indigenous religions particular to Africa. According to

Aida Seif El Dawla, there are not only supporters of FGC- there are women who have experienced the surgery who refer to the cultural custom as a religious edict.¹²⁸ An example that describes the connection of FGC to religion is the Keno people who live in Sierra Leone. Most of the Keno people uphold and maintain their indigenous religious beliefs, which are embedded in their culture, and include the ritual initiation of FGC.¹²⁹ Moreover, Ellen Gruenbaum explains that based on Egyptian religious scholars, FGC is an “Islamic practice mentioned in the tradition of the Prophet and sanctioned by Imams and Jurist.”¹³⁰ Forbidding sexual relationships outside of marriage is fundamental to the Islamic faith. The prohibition is connected to the use of FGC. The adherence to this religious cultural tradition inspires the use of FGC to meet the obligation. The religious rationale for FGC remains at the seat of the debate on FGC. While the rationale of religion is explored earlier in this dissertation, it is important to note here because of its cultural significance to FGC. Its significance is in FGC’s link to identity and identity to social status. Considering the cultural significance of religion and its association to social status is relevant. The relevance is in thinking about the practical use of respect for diversity when caring for women who choose FGC.

v. Improvement of male sexual pleasure and performance

Improvement in male sexual pleasure and performance is not one of the main reasons or rationales cited for FGC surgery. Nevertheless the brief but frequently mentioned theme of male sexual pleasure and improvement in performance is ongoing. It is curious that the subject is mentioned in a way that influences opposition to practice often juxtaposing the circumcised female and the absence of sexual pleasure and satisfaction with the increased pleasure of men. The query is raised- is the heightened sexual pleasure allegedly experienced by men a consequence of circumcision, therefore attributing to the improvement of sexual performance in

men? Does the theme of improved sexual performance and pleasure for men matter? It is important to note before moving further in the discussion that sexuality in the traditional African contexts is different from the perceptive of sexuality in the Western context.¹³¹ Furthermore scholars explain that there is no known specific research related to African sexuality and FGC, therefore to solve any sex related problems for Africans is done so in the context of Western understanding of sexuality leaving the sexual information regarding FGC antidotal.

Interestingly, on the idea of sexual pleasure and improvement in men, scholars inform that there is another perspective. Rendering her research on FGC and the subject of male sexual pleasure and improvement, El Dawla describes that Egyptian women have a different experience. Egyptian women feel entitled to sexual pleasure and report that they are sexually compatible with their partners and acknowledge that there is no difference between them and uncircumcised women.¹³² El Dawla further notes her research found that men often report, “it is harder to satisfy an uncircumcised women,”¹³³ and had no reports from men regarding increased improvement or pleasure. On the other hand, however, Asma El Dareer explains that doctors have commented that when the vaginal orifice is tight the pleasure for men is more acute, but of shorter duration. The sexual stimulation of men mentioned in the debate raises the query how the non- therapeutic surgery is any different than the vaginoplasty: a cosmetic procedure that some surgeons claim the surgery improves sensitivity.¹³⁴ Some Muslim scholars according to David Gollaher have argued that FGC, namely the removal of the hood of the clitoris makes both men and women more sensitive during intercourse and more likely to please her partner.¹³⁵ From Gollaher’s point of view the surgery has the potential to have heighten sexual stimulation for both partners and not just men. It is interesting to note that with regard to the sexual implications of FGC, both the positive and negative, some writers criticize the western feminist writers whose emphasis on the

sexual enhancement is nothing more than an exaggerated western obsession with sex.¹³⁶ What is additionally unsettling about the intensified focus on sex is that this obsessive focus portrays African and Arabic men and women as hypersexual and takes away from the embraced cultural ritual so embedded in tradition. This Eurocentric attitude, which perhaps imposes the sexual obsessiveness of western society, namely the U.S., cheapens and dilutes this traditional cultural practice which has been inherited, passed on from generation to generation and is part of the cultural heritage of many FGC cultures.

vi. Cultural heritage and social integration

Cultural heritage is one of the principles of global bioethics. It is defined by UNESCO as the “legacy of physical artifacts and intangible attributes of a group or society that are inherited from past generations, maintained in the present, and bestowed for the benefit of future generations.”¹³⁷ According to UNESCO, the term cultural heritage encompasses several main categories of heritage:

- Tangible cultural heritage
- Movable cultural heritage (paintings, sculptures, coins, manuscripts)
- Immovable cultural heritage (monuments, archaeological sites)
- Underwater cultural heritage (shipwrecks, underwater ruins and cities)
- Intangible cultural heritage: (oral traditions, performing arts, rituals)

Adhering to the UNESCO framework of cultural heritage, FGC is connected to intangible culture heritage, which specifically encompasses cultural rituals. Intangible cultural heritage is the customs of a particular culture that people practice. As investigated in chapter one of this dissertation the history of FGC, i.e., ritual cutting dates back to 2400 B. C. Gollaher explains about the history of male circumcision that carvings show that circumcision of males dates back to 2400 B.C where the carving explicitly shows the depiction of a surgical operation on the male genitalia. The inscription, according to Gollaher, reads, “ hold him and do not allow him to faint-

I will cause it to heal.”¹³⁸ Circumcision, whether of males or females, seems part of the cultural heritage of circumcising communities including the U.S. where male circumcision is embedded in the health care culture.

In Egypt, however, the religion of Islam has acknowledged FGC as a rightful counterpart to male circumcision.¹³⁹ While there are scholars who argue that FGC is not a religious custom but a cultural one,¹⁴⁰ nevertheless, in the historical context, Egypt revered and consecrated circumcision. Circumcision was preserved, protected, and given a place of honor as a religious and social practice.¹⁴¹ As circumcision is related to ritual and traditional customs and practices to intangible cultural heritage, it is critical to note the ceremonial custom was established in the form that would become familiar to Judaism, Christianity, and Islam by the religion of one of Egypt’s subject peoples the Israelites, and thus has been handed down through the years.¹⁴²

What is often noted in the literature, rather than fully explored by western feminist writers, is the ceremonial ritual aspect and celebration associated with FGC and the changes that have taken place over the years. One significant change noted in the scholarship on the celebratory aspects of FGC is that, in modern times, after the celebration and the circumcision, since the girls now have access to education, the time spent in the “bush” is now a couple of weeks instead of the several months.¹⁴³ The ceremonial ritual is important to the culture and to the heritage of FGC communities, as the practice symbolizes a change in the initiated persons social position.¹⁴⁴

Cultural heritage is an expression of a way of life of established by a community and passed on from generation to generation; it includes customs, practices, places, objects, artistic expression, and values. Cultural heritage includes traditions inherited from the ancestors and passed on to our children, for instance the cultural tradition of FGC. Is the cultural tradition one that can be

called cultural heritage using the UNESCO framework it is evident that FGC and male circumcision are part of the cultural heritage passed on through the generations of FGC communities. It would seem that FGC is part of the cultural heritage of religions, including indigenous religions, tribes, ethnic groups and communities. FGC is a cultural expression that embodies a way of living architected by a religious community and passed on from generation to generation. While the custom has been performed in ways that are allegedly harmful, i.e., the harmful consequences associated with FGC, there are frameworks that reduce medical consequences. Medicalization of FGC is one framework being used in FGC communities. In addition, scholars writing about FGC argue that the conflation of varied practices of FGC that results in an overemphasis on infibulation is unjustified.¹⁴⁵ They further explain the reality that infibulation is a rare practice that is associated with a specific region and interpretation of Muslim purdah ideology.¹⁴⁶ Moreover, according to Ahmadu, gynecologists explain that FGC does not pose any significant adverse long-term effects to women and that, on the whole, traditional circumcisers are “well trained and are experts” at what they do.¹⁴⁷ Observing FGC through the lens of cultural diversity is useful in observing FGC as intangible cultural heritage (ICH).

What is curious is that FGC must meet particular standards to be recognized as an intangible cultural heritage; it must be consistent with human rights and exhibit the need for mutual respect.¹⁴⁸ The human rights debate is quite often argued as a reason to eradicate the practice of FGC. According to Rahman and Toubia, the provisions of some of the human rights treaties have been interpreted in such a way as to support abandonment of the practice.¹⁴⁹ In addition, other scholars have argued that, not only is FGC a violation of human rights, it is unethical- a subject investigated earlier in this dissertation. Concerning the recognition of FGC

as an intangible cultural heritage, Kurin further explains that both the human rights and the mutual respect framework are very high, calling them both standards that are idealistic and impractical.¹⁵⁰

While the recognition of FGC as an intangible cultural heritage, has a long way to go, the concept of intangible cultural heritage has meaning for FGC, and specifically for women in need of care who choose FGC. One of the implications of intangible cultural heritage for FGC is that ICH helps to influence cultural diversity and respect for cultural diversity. While mutual respect is one of the standards for recognition, ICH can support and facilitate respect for differences among cultures and their cultural customs, especially in non-FGC communities. ICH is an important aspect in maintaining cultural diversity, as it encourages mutual respect for other ways of life.¹⁵¹

An understanding of the intangible cultural heritage of different cultures, ethnic groups, and practices facilitates respect for the values of others even when there is disagreement. In FGC communities, the community plays an important part, as mentioned in the earlier section. The cultural custom is identification with the cultural heritage, and the ceremony is an initiation into the cultural heritage of the community. FGC establishes the identity as a member of the ethnic group and unites those who are undergoing FGC with the ancestors, a feature in African cultures that is essential to the values and beliefs of the people.

B. Cultural Rights and FGC

This section will focus on the idea of cultural rights. Cultural rights are a prominent feature in the scholarship pertaining to FGC and are, at times, paired with human rights. Michel Revel refers to the idea of human rights and cultural rights as a “dual relationship”¹⁵² This section focuses on the cultural rights and human rights relationship as it relates to women who will

choose to undergo FGC. The dilemma for these women who now live in a non-FGC reality is how to continue to practice the rituals of the culture to which they are accustomed. Are these women protected by cultural rights- in other words do they have a right to culture? To abandon these cultural traditions has consequences that include rejection from their families and community, and rendering them outcasts. The weightiness of societal pressure, and the obligation to cultural customs outside their geographic location, are quite persuasive, making it probable that attempts to practice FGC underground are likely to occur, and further contribute to the danger and alleged harmfulness of the practice and the need for care.

Cultural Rights are rights related to art and culture, both understood in a larger context. The aim of cultural rights is to guarantee that people and communities have an access to culture and can participate in the culture of their election. Cultural rights are human rights that aim at assuring the enjoyment of culture and its components in conditions of equality, human dignity, and non-discrimination.¹⁵³ They are rights related to themes such as language; cultural and artistic production; participation in cultural life; cultural heritage; intellectual property rights; author's rights; minorities and access to culture, among others.

The *Universal Declaration on Cultural Diversity* highlights the dual interdependence of human rights and cultural diversity. Article 4 titled 'Human rights as guarantees of cultural diversity' explains the defense of cultural diversity is an ethical imperative, not able to be separated from respect for human dignity and implies a commitment to human rights and fundamental freedoms...¹⁵⁴ This indication of human dignity, human rights and fundamental freedoms is very much linked to the women who choose to undergo FGC surgery. This is particularly true when women make the choice for FGC in cultures that are non-FGC communities. Since FGC is often deeply associated with religious traditions, do women not have

the right to undergo the procedure based on their faith and religious beliefs? The same is true for women whose religious beliefs do not require them to undergo FGC.¹⁵⁵ Is choice not a human right and a bioethical imperative? It seems that much of the application to the human rights framework used against FGC is linked to health consequences and women who have no choice. If the alleged health consequences are debunked, especially through medicalization, and women indeed make a choice to undergo the FGC, is this not an infringement on the rights of women to exercise their religious freedom?

According to the Declaration, universal Human Rights afford expression of individual cultures, as long as they do not violate the human rights of all people as guaranteed by international law.¹⁵⁶ Individual cultures that have characteristics that distinguish themselves as spiritual, material, intellectual, or emotional features are what make up culture.¹⁵⁷ These aspects of individual cultures also embrace and embody “lifestyles, ways of living together, value systems, traditions and beliefs,”¹⁵⁸ all features of FGC communities. Human rights are rights that apply to all people. Furthermore the Declaration notes that, since human rights are universal, they “guarantee the particular expression of individual cultures.”¹⁵⁹ It is here that the dual interdependence of human rights and cultural rights seems at times to be in conflict with each other, perhaps creating competing interests.¹⁶⁰ The competing interests of each other foster different areas of tension.

For example, the assurance to express one’s culture on the one hand, and on the other the need to protect the universality of human rights of all people without violating them. Additionally it is the mutual dependence of cultural diversity and human rights that raises the question about the value of cultural diversity.¹⁶¹ There are both helpful and constructive aspects and adverse aspects of the concepts of cultural diver¹⁶²sity and human rights that cause

uncertainty or indecisiveness. However, as it concerns discerning what the care should be for women who choose, using the lens of cultural diversity is helpful. It is helpful in observing that the autonomous right for women to choose is at stake if cultural diversity and human rights are not considered in the construct of care. Therefore, the right to culture vis-a-vis human rights, must be included in establishing a model of care for women who choose FGC, especially in non-FGC communities.

Another concern relevant to the care of women, who choose FGC, is the issue of the right of members of minority groups. The *Universal Declaration on Cultural Diversity* states that there is a specific commitment to protect the rights of peoples who belong to minority group.¹⁶³ The minority status is particularly relevant to women who live in non-FGC communities and choose to practice FGC. In non-FGC contexts, the surgery is often practiced among immigrant i.e., refugee women. A decision made by a person of power, for instance the health care practitioner, who does not do the surgery could be regarded as infringement of the cultural rights and the autonomy of the refugee or immigrant women. Ignoring or not taking into consideration the autonomous decision of the patient does not foster the goal of medicine- the improvement of quality of life for the women who seek care.¹⁶⁴ Minority groups, especially women whose life intention is FGC, are often powerless to refute the decisions and judgments made about their cultural practices by those in the majority group.¹⁶⁵ Minority communities have the right to practice their culture i.e., FGC. The right to practice cultural rituals, however, cannot violate the human rights of others.

Applying cultural rights to FGC, specifically to women who live in non-FGC contexts and choose to participate in cultural rituals and practices in which they are accustomed is an integral feature of respecting cultural diversity. It is in the discussion regarding culture that cultural and

ethical relativism are raised. In addition, due to the interdependence of cultural rights and human rights, cultural diversity serves as part of the framework of care for women who choose FGC surgeries. The cultural practice endures because it makes sense to the members of the culture.¹⁶⁶

III. Forms of Relativism and FGC

This section will study the concept of relativism, particularly cultural relativism and ethical relativism. The analysis will focus on the question of how the two notions are employed in discerning the moral status of FGC and what should be the model of care for women who undergo the surgery. The framework of relativism argues that truth and morality occur in relationship to culture, which includes the historical context of a specific culture. Scholars will also assert however, that relativism is not absolute. Other scholars explain that relativism to “mean different things to different academic cultures”¹⁶⁷ Cultural and ethical relativism are features of the ongoing debate and scholarship concerning FGC and therefore they require further exploration as both have implications for discerning a model of care for women whose autonomous choice is to undergo FGC surgeries. Therefore, it is important to summarize with intention, the difference between cultural and ethical (moral) relativism, Ethical relativism is the concept that holds that morality is relative to the norms of one's culture. That is, whether an action is right or wrong depends on the moral norms of the society in which the action is practiced. The same action may be morally right in one society but be morally wrong in another. According to Manuel Velasquez, anthropologists describe a host of practices and traditional customs that are considered morally acceptable in some cultures but criticized in others, including infanticide, genocide, polygamy, racism, sexism, and torture.¹⁶⁸ Velasquez further suggests that the diversity of differences may lead to the consideration of whether there are any universal moral principles or whether morality is merely a matter of the cultural preferences and

perceptions.¹⁶⁹

Loretta Kopelman would agree with Velasquez that ethical relativism means morality is something that is relative to the norms of one's culture. That is, "if an action is right, it is approved by the culture; and conversely if an action or behavior is wrong, it is disapproved by the culture."¹⁷⁰ The culture makes the moral judgment. For example, as it relates to FGC, the implications of ethical relativism would suggest that since the culture approves the custom, the practice of the FGC is morally right, within the culture where it is approved and likewise, if there is disapproval, then FGC is morally wrong.¹⁷¹

Cultural relativism on the other hand means that in a particular cultural context certain behaviors and actions are right, as they are relative to the culture. The fundamental point in cultural relativism is that the action or behavior is right in the context of a particular cultural. However, that is not to say that the concept of cultural relativism means that all customs are equally respected and valued, they are not. For instance FGC is an accepted cultural practice in some cultures, particularly in Ethiopia, however in other cultures in Africa the practice is now forbidden.¹⁷² According to Kopelman she observes cultural relativism as another version of ethical relativism.¹⁷³ Kopelman asserts "to say something is right means it has cultural approval; to say something is wrong means it is disapproved by the culture."¹⁷⁴ Kopelman further explains, "Relativism means different things to different 'academic cultures,' because the term is used in so many different ways."¹⁷⁵ Nevertheless, for the purposes of this dissertation cultural relativism considers that people's perceptions, viewpoints, behaviors, beliefs and values are relative to their specific culture. Therefore, certain actions are right according to the cultural context. If the culture approves, the action is right. On the other hand, ethical relativism concentrates on what a specific culture judges or approves to be right or wrong.

However, to say something is approved does not settle whether it is wrong or right. An action can be wrong even though it is approved by most of the members of a culture. For example slavery was approved but its approval did not settle whether the action was right or wrong. Kopelman further argues there is no way to evaluate moral claims across cultures if cultural relativism is the standard by which to make judgments.¹⁷⁶ In fact they are not expressing judgments rather they are conveying their point of view.

One of the implications of cultural relativism for FGC is that the cultural tradition must be analyzed in the context of cultural diversity examined earlier in this chapter. Another implication for FGC and ethical relativism is what is judged unethical by one cultural, for example FGC in non- FGC contexts, could be viewed as morally acceptable in another which is at the seat of the debate. A third implication for FGC as it relates to both cultural and ethical relativism is the theories offer ongoing examination of defensible reasons, and explanations related to the research for the cultural practice that can help assess moral judgments across cultures in a way garners authority, particularly for women to choose FGC. The examinations of defensible reasons as highlighted throughout the dissertation make room for a less negative and hostile response to FGC, which facilitates a more balanced dialogue that includes the right for women to choose.

A. Cultural Relativism

Cultural relativism affirms that all cultural beliefs and values are equally justifiable depending on the cultural environment. Scholars of cultural relativism argue that all religious, ethical, aesthetic, and political beliefs are completely relative to the individual within a cultural identity and that an individual's human beliefs and activities should be understood by others in terms of that individual's own culture.¹⁷⁷ It has high regard values, beliefs, etc., from the point of view of

the culture, namely the insider or the emic perspective, discussed earlier in this chapter. Cultural relativism also means that no one culture is superior to another culture. That is: no one culture ranks higher than another culture or having the judgment and final say on what is right and what is wrong for all cultures. Cultural relativism is one way of avoiding ethnocentrism and judging another culture by the standards of one's own culture. Cultural relativism contends that groups and individuals hold a diverse set of values, beliefs and practices that must be respected. Cultural relativism holds that culture is the primary and major source that validates a moral rule or what is morally right.¹⁷⁸

While the cultural relativism approach appears unassuming in its assertion that values, beliefs, and practices for example should be understood in the context of the individual's cultural identity, Lane and Rubinstein, describe that cultural relativism is complex and encompassing. According to these authors, cultural relativism questions how much can be understood of the realities of other cultures and what might be the avenues for appreciating and understanding realities that are different.¹⁷⁹ Cultural relativism can also be understood as the reality of being able to fully relate to or comprehend the experience of other cultures in order to make a sufficiently balanced evaluation and judgment is extremely difficult. Its difficulty lies, according to Spiro in that "cultural patterns provide the template for all human action, growth and understanding, including what we think and feel, then all human social characteristics are culturally determined."¹⁸⁰ It is important to note here that this is one perspective, however a compelling one as it relates fully being able to understand the reality of others, namely women who choose FGC surgeries.

It is compelling because it makes tangible the reality that variation and diversity of cultures are limitless.¹⁸¹ An illustration of the variations and inexhaustible nature of culture is FGC.

While FGC is often attributed to Africa, FGC can be found all over the world as noted in chapter one of this dissertation. Due to transmittal of FGC from tribe to tribe, country to county, and religious tradition FGC surgeries are not same, although the current scholarship would support this claim. For example, there is a tendency in the FGC debate to claim that most of the surgeries are infibulation.¹⁸² However, after further investigation there is a variation of the cultural tradition. The variation includes a minor prick to draw a small amount of blood to the removal of the clitoris, i.e., infibulation. In addition there are differences in religious traditions and the practice of FGC. An additional variation not visible in the literature on FGC is the insider or emic voice of those women who embrace the cultural tradition practice.¹⁸³ From the cultural relativism viewpoint, that is, taking into consideration the difficulty in comprehending the reality of others in order to make unbiased judgment, it is possible to view FGC for women who choose through the lens of cultural diversity. In doing so the cultural practice can be better understood from an emic perspective. Culture is valuable. It is through having access to culture that people, namely women who choose to embrace their cultural traditions and practices have access to a diverse range of meaningful choices.¹⁸⁴

Concerning cultural relativism, a typology is useful that reflects the complexities,¹⁸⁵ but also illuminates frameworks for the consideration of cultural relativism. Lane and Rubinstein explain that there are three types of cultural relativism-descriptive, normative and epistemological, however it is descriptive and normative forms of relativism that are relevant to this dissertation. On their account, descriptive relativism suggests acknowledgement of the diversity of cultures that include behaviors and beliefs; normative relativism suggests an acceptance across cultures of their moral judgments as acceptable for that culture; These two types of cultural relativisms are helpful in discerning what the care should be for women who

choose FGC, particularly when the care needed is in non-FGC environments.

Descriptive relativism describes what is present in the current U.S. health care culture in the U.S. There is an acknowledgement of the differences in practices, beliefs, values, and religions of other cultures; however, the recognition does not lead to an appreciation or acceptance of cultural diversity. Descriptive cultural relativism is a result of the judgment concerning what is true for one culture and not another,¹⁸⁶ for example, FGC. According to Spiro social characteristics are corollary to culture and descriptive relativism is a by-product.¹⁸⁷ In other words the customs, beliefs and values of human groups depends on the culture and the range of variations between the cultures.

The rejection of diversity of cultural norms, and values causes moral disagreements between culture and individuals who chose to embrace beliefs, religion and cultural ritual traditions, namely FGC.

On the other hand cultural normative relativism implies an acceptance of the diversity of cultures and the variations of values, practices and beliefs of cultures.¹⁸⁸ In addition cultural normative relativism looks favorable regarding the moral judgments for that culture. That is, normative relativism allows for judgment of behavior according to the cultural context and respecting the evaluation of practices by the cultures own standard. Cultural normative relativism asserts since all standards are culturally constituted there is no available transcultural standard by which different standards are judged on merit or worth.¹⁸⁹ There is no standard pan-cultural standard by which cultures can be judged. That is, there are no standards across cultures that apply to cultures regardless of race, country or religion. One of the tensions in the FGC debate is that much of the discourse and evaluation of the FGC surgery is not done in the cultural context of FGC communities;¹⁹⁰ rather it is done using an ethnocentric gage. This is not to say that

cultural practices, particularly FGC should not come under ethical examination, it should.

However, the examination must be balanced and evaluated through the lens of cultural diversity rather than solely an ethnocentric one.

B. Ethical Relativism

Ethical relativism, sometimes referred too as moral relativism is often a controversial position concerned with the differences in moral judgments across cultures, societies, and communities.¹⁹¹ Ethical relativism is the theory that holds that morality is relative to the norms of one's culture. That is, whether an action is right or wrong depends on the moral norms of the society or culture in which the action is practiced. The action is right if it is approved in an individual's culture and wrong if the action is disapproved by the person's culture. If something is right, this means that the action or behavior has been approved by the culture, and if it is wrong the act, value, and practice. It is culturally disapproved. Loretta Kopelman explains that ethical relativism is sometimes called cultural relativism and implies that it is impossible to judge moral claims across cultures.¹⁹² She contends that positions taken by international groups, for example, WHO, merely reflect a group of particular societal opinions and have no moral standing in other cultures.¹⁹³ Further, according to this view it doesn't make sense to say that practices, beliefs, and values in another culture are wrong, when in fact, these things are approved- or to say that something is right, yet it is disapproved within the culture.

For instance, the same action may be morally right in one culture or society but morally wrong in another. An example is polygyny. The marital practice of polygyny is quite prevalent in Nigeria.¹⁹⁴ Polygyny is practiced across educational, socio-economic levels and religions, however most are Muslim. In the U.S., polygyny is taboo and by law it is illegal. A second example is FGC, also a cultural practice that is both taboo and illegal in the US. The subject of

FGC raises a plethora of robust opinions and vigorous moral judgments. To have moral opinions and judgments about beliefs, customs, values and practices within one's culture is an expression of that particular individual's cultural point of view. Importantly, the opinion, judgment, or perspective has no moral authority in another culture.¹⁹⁵

One of the debates concerning ethical relativism is that there is no determination on what constitutes universal moral judgments. In the FGC scholarship, however, it is argued that human rights, is one such judgment.¹⁹⁶ On the other hand, some scholars describe that the meaning of human rights remains abstract and obscure.¹⁹⁷ Nevertheless, what is important to determine is how cultural diversity assists in discerning what the model of care should be for women who choose FGC. In considering care, ethical relativism offers valuable insight. In thinking about care, the value is in Macklin's explanation about making moral judgment. Macklin argues, "if we begin with the assumption that making moral judgments of other people's actions is a legitimate enterprise, then the chore is to justify such judgments by appealing to shared values."¹⁹⁸ Starting at this point offers Macklin, "allows for discerning the source of disagreement when it occurs."¹⁹⁹ Protecting human right, namely the autonomy of women to choose FGC can perhaps be embraced as a shared value. Concerning shared values, Kopelman offers that shared values and goals can be used to "assess whether FGC is more like respect or oppression, more like enhancement or diminishment of opportunity."²⁰⁰ It is in light of the notion of shared values that respect for cultural diversity is realized and relevant for discerning a model of care for women experiencing FGC.

Related to sources of disagreements in making ethical judgments, Macklin identifies that the first disagreement concerns the facts about the situation under analysis, namely FGC. The ethical debate concerning FGC is associated with the health consequences of FGC surgeries.

Ethical debates most often count on the evaluation and consideration of the consequences of the action.²⁰¹ For instance, opponents of FGC robustly contest the alleged health consequences linked to FGC. On the other hand, there are those who argue that the health consequences are rare, and the assessments of the consequences of FGC are untrue. For example, the Public Policy Advisory Committee on Female Surgeries in Africa writes, “mainstream reports and highly sensationalized complications linked to FGC surgeries are infrequent events and are the exception and not the rule.”²⁰²

The second disagreement regards the moral status of the object or individual key to the situation.²⁰³ It is important to note at this point that the idea of the moral status concerning FGC was more fully examined earlier in this dissertation. The third basis for disagreement occurs when values and priorities in a particular situation conflict or compete, also examined earlier in this dissertation. What is noteworthy about these sources of disagreements, relative to women who choose FGC surgeries and are in need of care, is that ethical resolution in intercultural and transcultural contexts may or may not happen. However, the contribution that an ethical analysis can make is to identify the source of disagreements and determine where a solution is forthcoming.²⁰⁴ Relating to the sources of disagreements and discerning a model of care for women who choose FGC, the facts about the alleged health consequences must receive ongoing analysis.

In addition, since the ethical debate is dominated by the alleged health consequences, the medicalization approach becomes an approach that gives resolution. Ethically the approach supports the bioethical construct of autonomy and the global bioethical construct of cultural diversity, which demonstrates the recognition of cultural values and its application discussed in the next section. In transcultural contexts, for instance, in Africa where FGC surgeries are most

prevalent, it is vital that the ethical viewpoint from “outsiders,” includes respect and acceptance of the values and beliefs within the cultural context of women who choose FGC. For example, outsiders or the “etic” perspective are those viewpoints from individuals who are not part of the FGC communities. This line of thinking denotes that the customs, beliefs, and values of other cultures, particularly FGC communities have meaning to the individuals who live in that cultural context. Within the context of care, especially for women who will choose FGC, respect for cultural diversity is promoted by insisting that cultural values and beliefs have deep significance and meaning to those who are in FGC contexts, and that cultural customs and traditions must be understood within the context of each culture.

One reality is that different cultures have dissimilar and diverse perspectives about what is right and wrong and what is good and bad. These differences are integral features of cultural diversity.²⁰⁵ In other words, whether an action is right or wrong depends on the moral norms of the society in which it is practiced and being judged.

Interestingly, there are numerous accounts for ethical and moral relativity. One in particular is concerning. It is the application of ethical or moral relativism that denotes that ethical standards, morality, and positions can be considered right or wrong based solely on culture and therefore subject to a person's individual choice. What is concerning about this use of ethical relativity in this way is that moral disagreements about culture, its practice or traditions, do not come under ethical consideration which makes it difficult for ethical or moral relativism to be considered as an effective model for discerning what is right and what is wrong.²⁰⁶ What is concerning about ethical relativism particularly as it relates to FGC, is that some scholars assert that moral relativism makes the claim that it is morally neutral.²⁰⁷ A morally neutral position is not acceptable, particularly for women who choose FGC and is in need of redress. If not, atrocities

such as slavery, the holocaust, and Tuskegee for example would go ethically unchallenged.

There are two moral versions for consideration, especially as they are concerned with discerning a model of care for women who undergo FGC surgeries. An implication specific to women who choose FGC surgery and in need of care is protection of their human rights, i.e., their autonomy. That is, if the standard for a health practitioner is morally neutrality then the principles under examination, i.e., respect for human vulnerability, non-maleficence and respect for autonomy would be debatable.

According to Edmund Pellegrino, the strong version of ethical relativism determines that there is no set of universal moral norms that can be applied with any authority or legitimacy for every human being universally.²⁰⁸ The strong ethical relativism framework appears to be a closed framework. The closed frame fosters exclusivity in that the moral framework resides inside the confines of the culture and only that culture. A cultural framework that is closed inhibits any idea of a universal set of principles because there is no way to assess one set of principles against the other and no way to judge the moral status of culture.²⁰⁹ That is, whatever a culture or society accepts as its practices, for example FGC, is what determines its morals. With regard to FGC, this line of thinking is unacceptable. For example, for girls and women to undergo FGC involuntarily and against their will is unethical and violates their right to autonomy and self-determination. Cultural practices must be able to stand up against rigorous moral scrutiny and ethical analysis. However, as mentioned earlier, the ethical analysis considers the values and beliefs within the culture in which the ethical analysis is taking place. All cultures are subject to ethical analysis.

A weak form of moral relativism, which begins also with cultural diversity, involves the use of principles. An example perhaps is the use of bioethical and global bioethics principles

examined in this dissertation that include autonomy, beneficence, non-maleficence and respect for cultural diversity. Principles used in the weak form of moral relativism do not change.²¹⁰ Principles are the most basic and primary source for ascertaining what is good or bad, right or wrong. Therefore, they serve as the groundwork for the judgment of a culture.²¹¹ The weak form of moral relativism allows for diversity of practices and customs but the moral principles are static- they remain the same. According to Pellegrino, the more fragile form of relativism promotes meaning discourse within the same cultures and between different cultures. Since principles are foundational or fundamental to the more fragile form of moral relativism and allow for dialogue among and between different cultures, the weak form of ethical/moral relativism is a consideration and relative to what the model of care should be for women who autonomously choose FGC surgeries outside of FGC cultures.

The relative aspects include the use of principles, as they are essential to discerning what is right and wrong, good or bad. The cultural diversity framework, applied to intra cultural and transcultural contexts, allows for respect for diversity of cultures. The weak version of ethical/moral relativism makes room for dialogue. This feature, allowing for conversation, is critical if cultures are going to attempt to understand and appreciate the difference in values, beliefs, and practices from a point of view that is less biased, hostile, and judgmental and is essential to care for women who undergo FGC surgery. Ethical relativism in this sense, for instance a weak form of moral relativism, assists in the application of cultural diversity to care.

IV. Applying Respect for Cultural Diversity to Care

The global bioethics principle of respect for cultural diversity is a framework and model of care for refugee women who choose to undergo FGC. While the ethics of care is more fully examined in chapter seven, the ethics of care lends itself to a model of care that includes respect

for culture diversity.²¹² The ethics of care framework's underpinning is predicated on the grounds that there is moral significance of attending to and meeting the need of others in which we take responsibility, namely the health care practitioner providing care for women who undergo FGC surgery. That is, applying cultural diversity to the context of care. It is in the context of care that the needs of the patient are realized and attended too. Since care is a relationship between the carer and the cared for, it is in the relationship that respect for cultural diversity is applied.

There is undeniable ethical significance to cultural diversity and care. Its significance lies in patient- centered care where the focus of care is on meeting the needs and preferences of the patient. In addition, when observing FGC through the lens of respect for cultural diversity FGC is not purely a destructive and superficial practice. Rather FGC is a traditional practice embedded in culture which has significance related to religious beliefs, values and ideals.²¹³ Respect for cultural diversity facilitates observing FGC within the context of culture where it finds it relevance. Therefore, in applying respect for cultural diversity, cultural sensitivity and cultural competency are also included. The cultural sensitivity framework and approach assists in advancing the occurrence of cultural connectedness between the health practitioner and the patient who is in need of care. Respecting cultural diversity takes into account the plurality of values, beliefs, customs and traditions of those who seek care, particularly women who choose to undergo FGC surgeries. It is a way of recognizing the cultural difference instead of refusing the difference.

Recognizing and understanding choices and life intentions from the “emic” perspective of different cultures is critical in applying respect for cultural diversity to care. Thoughtful consideration and appreciation of the insider's or “emic” viewpoint is key. It is essential to the relationship between the health professional and the women who have chosen FGC. It is this

viewpoint that can assist with a more accurate understanding of FGC. On the other hand, the importance of applying respect for cultural diversity is also in understanding with the “etic” perspective, that is, the viewpoint that the health professional brings to care relationship. The etic or outsider view will assist the health practitioners in their biases and support dismantling them. Gaining an understanding and appreciation of values, beliefs and customs from the viewpoint of the patient as they voice them rather than a place of sameness can help the health professional to dismantle biases and prejudices. These prejudices have implications that can affect the patient-health professional relationship, as these biases can facilitate the discrediting of the patient's autonomous choice.

Another aspect in applying respect for cultural diversity to care is in what Charles Taylor refers to as “recognition.”²¹⁴ According to Taylor, there are two forms of public recognition, “weak” and “strong.” Weak recognition is a form of acceptance of all people. People are formally considered equal regardless of their cultural or other differences. Individuals of all cultures are equal under the law, however, this does not take into account the special features and needs of the culture.²¹⁵ This endorsed and sanctioned form of recognition, if you will, is not enough to allow or support respect for individual differences. What the weak form of recognition does allow as it relates to differences, is a superficial recognition that has the potential to permit differences to be glossed over and ignored by the health practitioner, especially for women undergoing FGC.

As a result of this weakness, Taylor offers an alternative, *strong* recognition.²¹⁶ Taylor explains that strong recognition means that all difference must be respected and accepted by society. It is important to say however that cultural customs and practices that are imposed against the individual's desire, namely women who un-voluntarily undergo FGC, is

unacceptable. Respecting cultural diversity namely the variety found in culture customs, and practices of patients who are different is central to providing quality care. Respecting cultural diversity is undergirded by cultural competency and sensitivity toward the diversity in values, traditions and the beliefs of others. Since providing care takes place in relationship, which means taking responsibility to meet the needs of the patient, and then responsibility takes into account competency.²¹⁷ In other words, there is a responsibility for the health care practitioner to be competent in the areas that affects the relationship between the health professional and the patient, precisely cultural competency.²¹⁸

It is in the diversity of culture nestled in the dominant cultural construct under investigation that makes respect for cultural diversity a strong framework for discerning what the care should be for women who choose FGC. A sharpened sensitivity to culture and the right to embrace one's culture will enable respect for differences and similarities in the health care context. In so doing, care can be focused on the whole person who brings to the care relationship their values; beliefs, customs, and traditions that often inform their health care choice. In this way, the health professional can comprehend and appreciate the perspective of the patient as it relates to the choices made and the life intention of the patient, which facilitates the goal of care- to provide optimal care for all patients.²¹⁹

V. Conclusion

In the context of health care ethics, respect for cultural diversity is an ethical imperative. Respect for cultural diversity is an intimate feature of the patient-health care practitioner relationship, namely those patients who are refugee women choosing to undergo FGC surgery. Through the lens of cultural diversity, FGC is not merely a negative traditional custom worthy of censure. Rather it is a cultural practice that has relevance and meaning.²²⁰ The meaning found in

FGC is associated with identity, status and religion for example. The meaning and value is embedded in its cultural significance which has been transmitted from tribe to tribe, country to country, and generation to generation. Because FGC is a custom that has value and importance to the cultures engaged in the custom, cultural sensitivity and competence are necessary.

In the context of care, the importance of cultural diversity particularly when caring for women²²¹ experiencing FGC, lies in understanding the patient and the contextual influence at work in how she makes health care decisions. It is here that the cultural significance of FGC finds its worth in the care relationship and in constructing a model of care for women who choose FGC surgery. The social, societal, and the religious aspects associated with FGC are central to understanding a refugee woman living in a non-circumcising community requesting the surgery. The traditional custom is not merely an insignificant custom left behind from antiquity that has no worth or meaning. To communities who practice FGC, it is a deeply meaningful custom embraced by both current generations and future generations to come.

As FGC concerns care, respect for cultural diversity is critical to discerning a model of care for women who choose FGC surgery. An additional feature of the principle is that respecting the diversity of values, beliefs, traditions, and lifestyles of the patient impacts the goal of care. To foster an outcome that positively affects the quality of life for the patient is in the hands of the health practitioner. Therefore, it is incumbent on the health professional to be culturally competent so that he/she has the ability to respond effectively and positively to the needs of the patient.²²² Cultural diversity is promoted and realized by embracing the cultural values, traditions, and beliefs that have meaning for the patient, and by specifically understanding FGC within the context of culture.

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- ²¹⁷Ruud ter Meulen, "Ethics of Care," in *The Sage Handbook of health Care Ethics*, ed. Ruth Chadwick, Henk ten Have, and Eric Meslin (Los Angeles: SAGE, 2011), 43
- ²¹⁸See, Welch, Thomas. "Culture and the Patient-Physician Relationship: Achieving Cultural Competency in Health Care," *Journal of Pediatrics* 136 (2000): 14-23.
- ²¹⁹Galanti, *Caring for Patients*, 16.
- ²²⁰Gruenbaum, *The Female*, 107.
- ²²¹See, Dawson, A. J., S. Turkmani, N. Varol, S. Nanayakkara, E. Sullivan, and C. S. E. Homer. "Midwives' experiences of caring for women with female genital mutilation: Insights and ways forward for practice in Australia." *Women and Birth* 28, no. 3 (2015): 207-214. doi:10.1016/j.wombi.2015.01.007.
- ²²²See, Odemerho, Benedicta I., and Marjorie Baier. "Female Genital Cutting and the Need for Culturally Competent Communication." *Journal of Nurse Practitioners* 8, no. 6 (2012): 452-457.

Chapter 6: Respect for Human Vulnerability, Refugee Women and Care

This chapter will argue that the concept of respect for human vulnerability should be regarded as a significant tool in framing an adequate model of care for refugee women who will choose to undergo FGC. International Human Rights Law and the UNESCO *Universal Declaration on Bioethics and Human Rights* allow to connect the idea of human vulnerability to female refugees through its “ethically grounded” precept that asserts the inherent dignity and equality of all human persons.¹ Scholarship on human vulnerability describes the concept as ambiguous and argues that it is applied in a myriad of ways; therefore, the notion of respect for human vulnerability needs further investigation and clarification. Considering the weight that the notion has come to bear, especially in this dissertation, respect for human vulnerability is important to analyze.

I. Human Vulnerability

A. Defining Human Vulnerability

Scholars have offered a variety of definitions on the meaning of vulnerability. To affirm this assertion, the literature describes vulnerability as a notion that is unclear and ambiguous, especially because of the significance of the concept across disciplines.² Respect for human vulnerability can be difficult to understand and needs further clarification so that a working definition can be engaged. While the notion of respect for human vulnerability does not appear in the four underpinnings that make up the western construct of bioethics, it is a feature of both global bioethics and the UNESCO *Universal Declaration on Bioethics and Human Rights*. As it relates to bioethics, the concept of human vulnerability is found to be a most prominent feature in human research subject discourse with progress made toward health care ethics. According to

Henk ten Have, vulnerability is “no longer only relevant for medical research but also healthcare.”³

According to the Oxford dictionary, “vulnerable” comes from the Latin term *vulnerabilis*, which means, “wounding,” and from the word “ability,” which means, “being able.” Essentially, at its roots, vulnerability means the ability to receive injury. In other words, vulnerability can be defined as the “susceptibility of being wounded.”⁴ A common thread used in explaining vulnerability is susceptibility to injury and harm: mentally, emotionally, spiritually, and physically. There exists a broad spectrum in the use of the term vulnerability. It is a concept used across disciplines and in various areas of study. In some disciplines, for example the concept is used to make special note or reference to people or populations who are exposed to particular “risks or high risks”⁵. Health organizations for instance use the term vulnerable populations to refer to people and populations who are more susceptible to specific diseases or conditions more than others are.

The World Health Organization (WHO) uses the term vulnerability to describe threats to particular environments, for example in the context of climate change, nutrition, and disaster preparedness.⁶ Furthermore, WHO and other health care organizations and agencies employ the term to describe human health vulnerability and the vulnerability, for example, of human research subjects. Environmentalists also use the term vulnerability. Most often, they use the term to describe threats to particular environments. Nevertheless, the current concept of vulnerability remains ambiguous no matter the frequency of its use. One scholar suggests, “vulnerability is a notion that is rather vague, especially considering the weight it has come to bear.”⁷

The concept of vulnerability is often used in general terms without specific guidelines or a

framework for its application. One author notes, “It is one of the least examined concepts in research ethics and fails to address less settled situations arising for the context in which contemporary research is conducted.”⁸ Vulnerability seems to mean something different for everyone. While some scholars, practitioners, researchers, clinicians, and authors find common ground on the ideas of wounds and injury, both associated with the term vulnerability, others propose distinct differences in their definitions of vulnerability. Carol Levine, for example, includes in her definition of vulnerability “the concept of incapability,”⁹ a notion used in health care ethics to describe an individual’s inability to make medical decisions.¹⁰ She further discusses that vulnerability is associated with an individual’s ability to protect his or her own interests and explains “incapability of protecting one’s interest (health) exists because individuals have insufficient power, intellect, education, resources, strength, or other needs that attribute to protecting one’s own interest.”¹¹ Similarly Barry Hoffmaster offers that vulnerability means, “that one is controlled by, rather than in control of the world and marks the limits of our individualism.”¹²

Robert Goodin offers a more distinctive illustration of vulnerability by considering the concept of vulnerability as a “relational concept,”¹³ important in discerning a model of what care should be for women who choose FGC. The concept of vulnerability cannot be realized outside of relationships. Whether the relationship is doctor/patient, clinician/client, researcher/subject, or the like, these linkages of individuals are relational. To expand the relational concept described by Goodin, Tricha Shivas explains, “our understanding of relationships includes power dynamics and social and political circumstances.”¹⁴ The perspective offered by Goodin and Shivas can be applied to a diverse context, specifically FGC communities and women who choose FGC surgeries in non-FGC environments. Alexander Morawa’s investigates vulnerability

from the lens of international human rights. Morawa asserts there are no definitive definitions for vulnerability or how it is used and no classifications that are useful in its application.¹⁵ Carol Levine, for instance, argues that the concept of vulnerability is “both too broad and too narrow to be valuable or helpful,¹⁶ making its application difficult.

On the other hand, however, Maria Patrao Neves not only describes the relevance of the concept of vulnerability, she explains vulnerability as a principle and not only a concept. According to Neves, [Article 8]: Respect for Human Vulnerability and Personal Integrity, is included in the construct of the UNESCO *Universal Declaration on Bioethics and Human Rights*. The Article describes the “principles that should be observed and also makes clear the obligation of ‘respect for human vulnerability and personal integrity.’”¹⁷ The UNESCO Declaration develops a framework for vulnerability in which to observe the condition of FGC, particularly for women who choose the FGC surgery. In this construct, vulnerability is regarded as a human condition, characteristic of and intrinsic to the fragile state of being human, and therefore cannot be eliminated, requiring the care and responsibility of others.¹⁸

Human beings are susceptible to being wounded. The Barcelona Declaration of 1998 articulates that the notion of vulnerability encompasses both the finitude and the fragile nature of life. Further the Declaration explains that vulnerability is the object of a moral principle, which necessitates care for those who are in need.¹⁹ In addition, the Barcelona Declaration expresses that “the vulnerable are those whose autonomy, dignity, or integrity is capable of being threatened.”²⁰ In discerning what the care should be for women experiencing FGC, the Barcelona Declaration offered and incorporated into the UNESCO Declaration has positive implications for care. One example of the positive implications of care is that the Barcelona Declaration, 1988 specifically notes that vulnerability is applied to those who are prone to their autonomy being

refused. That is, for women who are requesting FGC in non-FGC communities such as the U.S., care requires sensitivity to her choice being disregarded. The concern is one articulated in Chapter 3 of this dissertation on autonomy.

The framework for vulnerability articulated by the Declaration is linked to Robert Goodin's expression of vulnerability in that he describes the principle as one that is relational. Another significant feature of the principle of vulnerability articulated by the Declaration is that vulnerability is tied to autonomy, a principle needed in establishing a model of care for women who choose FGC. Included also in the framework is morality, another feature in this dissertation as it relates to what decisions should be made on behalf of women choosing FGC who are in need of care. In other words, the moral judgment must be in harmony or agreement with autonomy.²¹ In constructing a working framework related to FGC, it is important to mention that, according to Jan Heige Solbakk, the Declaration operates from an anthropocentric idea of vulnerability in that the Declaration functions from the place of human life and human vulnerability rather than from the perspective of the fragility of life.²² Using the UNESCO framework for vulnerability assists in determining a model of care that focuses on human life and human vulnerability. It serves as an ethical anchor²³ that allows for stability and guidance in a situation that might otherwise cause indecision about how to proceed with care. Human life and vulnerability requires responsiveness, which takes place in the form of protection for those whose autonomy is capable of being impeded. In doing so, care works with the vulnerable among us, which can include populations of refugees, women, and children.

B. Who are the vulnerable populations among us?

According to some scholars, all human beings are vulnerable.²⁴ The vulnerability scholarship illustrates that vulnerability is not only regarded as a concept applicable for individuals, rather

vulnerability applies to communities, families, and groups who are also vulnerable.²⁵ The application of vulnerability offered by UNESCO explains that there are certain circumstances, which render vulnerability. These examples include disease, disability, other personal conditions, environmental conditions, and limited resources.²⁶ For the purposes of this dissertation, perhaps the category of other personal conditions is appropriate since the women in question are not research participants. One of the criticisms offered in the scholarship on vulnerability has to do with categorization.²⁷ For example, Morawa describes that there is an absence of a list and classification of individuals who can be classified as vulnerable.²⁸ Morawa further explains the interrelatedness of the criteria for each classification.²⁹ This interrelated nature of categories can be daunting in an attempt to assign vulnerability and the need for protection. An example of interrelatedness of classifications in defining those who are vulnerable will be described further when observing women and refugees examined below.

The list offered by Morawa is by no means exhaustive; however, it supports the claim that refugee women are deemed a vulnerable population and that employing respect for human vulnerability is critical in ethically examining FGC and in determining a sufficient model of care. A protocol for the use of assigning vulnerability includes the context of the individual or community at the time of application. For example, because of the diverse use of the term across disciplines, cultures, and fields of study, the term vulnerability will continue to be used, and its use will have difference meanings. Jonathan Moreno expresses that the term vulnerability is not going away, and that the term is often used to make crucial decisions regarding the lives of individuals and populations³⁰ particularly when the patient is unable to provide informed consent. Since informed consent is typically used in health care settings, context is important to consider. Employing the concept of vulnerability in this way is of the utmost importance.

However, the term reaches beyond the scope of informed consent. Vulnerability is what it means to be human³¹ and has application in other venues and contexts.

i. Refugees

In its legal sense, the term refugee represents protection that may be granted to individuals who meet the definition of ‘refugee.’ Refugees are generally people outside of their country who are unable or unwilling to return home because they fear serious abuse and loss of life. The term refugee is a legal term and implies a legal status. The United Nations Human Rights Commission (UNHRC) defines a refugee as “someone who has been forced to flee his or her country because of persecution, war, violence, or a well-founded fear of persecution for reasons of race, religion, nationality, political opinion, or membership in a particular social group.”³² A feature in what is included in determining refugee status is that refugees cannot return home. Not being able to return home is most likely due to fear of war, religious, ethnic, and tribal violence, which are also the leading causes of what forces refugees to leave their country. Refugees and the plight of refugees is rigorously examined in Chapter 2 of this dissertation. The purpose of highlighting the classification of refugees, specifically refugee women who live in non-FGC communities and chose FGC, is to highlight their vulnerability and their need for protection under the framework for vulnerability adopted by UNESCO [Article 8].

Since the traditional and cultural practice of FGC is extensive in Africa, it is prudent to mention the African context as it relates to refugee women and the communities of women and their families now living in the U.S. In a recent publication authored by Alexandra Toppings, she mentions that FGC affects three times more women and girls in the U.S. than previously thought.³³ While the article is aimed at eradication of the FGC, the information is critical to the reality of the practice in the U.S. For instance, Toppings notes “FGM is happening in New York,

and in Boston.”³⁴ The article is not clear about whether the women are refugees in the legal sense of the term or whether they are U.S. citizens; however, what is important is that these women are from contexts where FGC was/is part of their custom.

As refugee women relate to vulnerability, the idea of protection is a substantive theme in the scholarship on refugees³⁵ and is a benefit of overwhelming concern to refugees and those who care for refugees. Refugees are vulnerable to a number of efforts that promote harm.³⁶ For example, according to the UNHCR women are susceptible to sexual and gender based harm.³⁷ While all refugees are open to potential harm and abuses that includes human rights violations and various forms of violence, women remain particularly vulnerable. Women share the vulnerabilities that are experienced by all refugees. However, women and girls have special protection needs that reflect their gender.

ii. Women

According to Morawa, women are included in list of those who are vulnerable. Further, Morawa explains that the Convention of Belem do Para asserts that states will take special consideration of the vulnerability of women to violence by reason, their race or ethnic background, or their status of refugees or displaced peoples. Consideration should also be given in the same way to women who are exposed and in danger of being violated, minors, persons who are disabled, elderly, socio-economically disadvantaged, and those who are affected by war or deprived of freedom.³⁸ Importantly however, as it concerns women and the designation of vulnerability assigned, Ruth Macklin offers it is mistake to construe women in general as a class of human beings who are vulnerable, even though in parts of the world women are powerless and lack self- determination with both family and cultural context.³⁹ This is true in cultural contexts where they are powerless on a number of fronts, including the classifications noted earlier in this

section. On the subject of context, Ruth Macklin further describes that in the context of multinational regions, that throughout whole countries and certain cultures the powerlessness and oppression of women make them vulnerable.⁴⁰

Interestingly, Ruth Macklin offers the concept of being medically disadvantaged. This classification is relevant to women and girls who undergo FGC, either with permission or without. Often in FGC communities what is lacking is the adequate medical attention needed to perform the surgery and to care for women and girls after the surgery. Therefore, special attention must be given to those who are medically disadvantaged, particularly women in both FGC contexts and non-FGC contexts who undergo FGC surgeries. Women are deemed a vulnerable population and employing respect for human vulnerability is critical in ethically examining FGC and determining a sufficient model of care.

Relating to gender and vulnerability the specific need for protection consists of protection from sexual and physical abuse, exploration that leads to human trafficking, and protection from gender discrimination which makes being female a barrier to accessing goods and services. One theme that is central to gender specific protection is protection from FGC, which is described as violence against women and a violation of human rights. It is noteworthy to mention that gender violence is one viewpoint that opponents of FGC use as a platform to eradicate FGC. In light of cultural diversity, however, and the situation where refugee women who now live in non-FGC contexts make the decision to undergo FGC surgery, the cultural custom is not gender violence; rather it is an autonomous choice. Vulnerability relates to refugee women and FGC in protecting their right to self-determination.

On the other hand, however, protection must be given to those women who do not wish to undergo FGC. Women, namely refugee women who involuntarily experience FGC are in need of

protection. Undergoing FGC without consent or permission threatens both the autonomy and the dignity of women.⁴¹ Involuntary FGC is not only unethical, involuntary FGC is characterized as one form of gender-based violence. For instance the UNHCR considers “FGM to be a form of gender-based violence.”⁴² In addition, the FGC literature describes FGM not only as a violent act against women it is described as a form of persecution, especially in human rights law. The UNHCR deems all forms and types of FGC a violation of the human rights of women and girls. Furthermore, FGC is established by the UNHCR as a well-founded fear of persecution for both women and their daughters. The literature reflects that there is both the fear of being forced to undergo the procedure and the fear of facing persecution for refusing to force their daughters to have the surgery. Because sexually based gender violence can occur at any time during the stages of the refugee cycle, the idea of “human security raises the awareness of threats against the physical security of refugee women,”⁴³ and in need of protection.

Women from ethnic minority groups are also classified as those who are deemed vulnerable and in need of protection. Ethnicity and FGC as it concerns vulnerability is discussed later in this chapter. Feminist writers and scholars use the term vulnerability, but have not examined the concept in depth. It seems, generally, that vulnerability is associated with and is central to women.⁴⁴ Hollander asserts that gender, danger, and violence are integral to being female and argues that vulnerability to violence is “a core component to femininity but not masculinity.”⁴⁵ Leading scholars would agree with the claim that violence is related however, would disagree with the generality made. Macklin contends, “it is a mistake to construe women in general as a class of human beings who are vulnerable.”⁴⁶ However, Macklin makes a more specific claim concerning women and vulnerability.

From a global and international perspective, women in many parts of the world “lack power and self-determination within family and in the culture and are subjected to physical harm and psychological degradation.”⁴⁷ Vulnerability with respect to physical and psychological harm is more specific and pervasive in the lives of women.⁴⁸ Nancy Jecker asserts that feminists call for attention to vulnerability in a myriad of ways in which unconscious racism, sexism, homophobia, ageism, and ableism pervade our judgments about people and policies.”⁴⁹ Additionally, Jecker illustrates how fear, exclusion, and discrimination are pervasive in the context of research design and to change the tenure of research these issues must be addressed.⁵⁰

Feminist scholars uniquely take into account the social structures that cause vulnerability. For example, sociologists frame the family as a natural universal social structure.⁵¹ However, in the context of family, it is customary for the structure of a family to be patriarchal in nature and deemed as a private component of society. In describing the ethics of care, Virginia Held writes that the family structure is a “private sphere beyond politics which government, based on consent, should not intrude.”⁵² Concerning social structures and vulnerability, when describing health choices particularly related to women, Lisa Cahill describes contextual considerations which include addressing the social barriers and constructs that do not afford women equality but fosters their oppression,⁵³ and poverty, therefore, leaving them powerless, and contributing to their vulnerability.

Feminist researchers and writers have illustrated how the obvious power structures are prevalent and prevail in society, for instance, financial and profit making structures, government structures and “the cultural power of men.”⁵⁴ These structures have constructed “private”⁵⁵ spaces for woman and children that are not in the best interest of woman. These constructed spaces leave them open to harm and injury,⁵⁶ therefore rendering them vulnerable. It is in light

of injury and harm, (vulnerability) that Jocelyn Hollander argues that a “vulnerability to violence”⁵⁷ is centrally associated with being a woman, an idea in which feminist scholars based on the scholarship would agree.⁵⁸ The concept of vulnerability asks us to respond, however scholars propose that responsiveness suggests obligation and responsibility.⁵⁹

Ruth Macklin echoes this sentiment of the vulnerability of refugee women. She explains that in the context of multinational regions, throughout whole countries and certain cultures the powerlessness and oppression of women make them vulnerable.⁶⁰ As discussed, women make up approximately half of the world's refugee population. Refugee women are particularly vulnerable, and the circumstances of their refugee status put refugee women at risk for harm and injury and in need of protection. The impact that violence has on women refugees is devastating. The pervasiveness of sexual and physical violence, and human rights abuse among refugee women, and girls, is staggering.⁶¹ For instance, one such example of violence experienced by women fleeing persecution is gender-based violence. Gender-based violence takes the form of, “domestic violence, trafficking, enforced prostitution, and sexual violence.”⁶² These forms of cruelty and aggression include “rape, forced impregnation, forced abortion, sexual slavery, and the intentional spread of sexually transmitted infections, including HIV/AIDS.”⁶³

Refugees, especially those who have insufficient means, are not only susceptible to external threats, for example the oppressive governing social order, but they are open to internal threats, as well. External threats are vulnerabilities that threaten one’s opportunity to participate in the mainstream of life. One example of an external threat that impedes the ability for refugee women to participate in life in a holistic way is not having “equal access to food, water, and non-food items.”⁶⁴ Not having access is a fundamental issue facing refugee and displaced women and their children. Internal threats are features of individuals such as age, sex, and genetics which can

influence a biological response to not having access to food and non food items”⁶⁵ An opportunity to participate in the mainstream of life rather than on the margins should be afforded not only for refugee women. Seemingly, to provide both refugee women with access to assistance and support is what morality might recommend. Affording access is what it means to be treated with dignity.

iii. Children

Children, namely girls, are not the focus of this dissertation. However, it is noteworthy to mention the vulnerability of girls as it concerns FGC surgery. Its importance lies in the unethical nature of undergoing FGC against the will of young girls or the guidance of the parents, which places girls in very vulnerable circumstances. In a recent study done by the Center for Disease Control, the report describes that the number of women and girls living with or at risk from FGM in the US has increased from an estimated 168,000 to 513,000.⁶⁶ These figures reveal that the number of girls, under the age of 18 years old, and at risk for undergoing FGC, has quadrupled, since the last prevalence study was done in 1977.⁶⁷

As it concerns vulnerability, girls who are at risk to undergo FGC against their will are deemed vulnerable. Girls from infancy to five years old, depending upon the cultural region are the primary focus of FGC.”⁶⁸ The girls who are forced to undergo FGC are powerless and do not have the ability to protect themselves or their own self-interest. It is here that Carol Levine’s argument that the inability and powerlessness of protecting one’s interest because individuals have inadequate means to do so,⁶⁹ is understood and brought to fruition.

Bringing the vulnerability to fruition then requires a response examined later in this chapter, the response to protect. Children, it is argued, are not capable of giving consent. In the FGC research according to Efua Dorkenoo, young girls often experience FGC without the

consent of their parents.⁷⁰ Because of the embedded cultural tradition it is a “given” if you will, that the FGC traditional custom is followed. Interestingly, the scholarship on FGC describes that there are instances, however, where mothers have taken their girls to other countries so that they are not forced to undergo the surgery. The involuntary status of FGC fosters the asylum status highlighted in the literature, where families will flee their home to protect their daughters from FGC.⁷¹ Certainly, forcing a child and her parents to undergo the surgery is a violation of the human rights of the child, a prominent theme in the FGC debate.

The debate argues that children’s rights include their right not to have surgical changes to their bodies before they are old enough to decide for themselves.⁷² Doing so is, without question, a violation of the bodily integrity of girls and women who do not choose FGC. Therefore, human rights law grants children special protection.⁷³ In addition, the role of the parent in giving guidance and direction in the exercise of children’s rights must be valued and followed.⁷⁴ It is important to very briefly mention some of the alleged negative circumstance of FGC and young girls. As it relates to health, girls suffer some of the same consequences that the research reports women experience. For instance, Loretta Kopelman found that “psychological disturbances in girls due to circumcision are not uncommon.”⁷⁵ The research explains that women, who had the surgery as children, and against their will, have psychological effects that can be characterized as anger and trauma.⁷⁶ The psychological effects have the ability to follow a person through her life, thus affecting girls who are circumcised into adulthood.

On the other hand, however, some of the research reflects the embedded nature of FGC as it relates to girls and is part of a wider cultural ethos connected to reasons for FGC. An example of these reasons is illustrated in field studies conducted that highlight the two main reasons attributed to circumcising women and girls. The first reason noted is that the practice

reduces a women's sexual desire, thus preserving the young girl's virginity until she is married. In Africa, a circumcised female is a prerequisite for marriage. The girls in parts of Africa are married quite young. Marriage is associated with security and security with the economic nature of the traditional practice. Other scholarship on FGC offers that circumcising girls is used as a way of protecting young girls against sexual violence such as rape, a reason that is not often fully investigated.

The second reason for circumcision given by the women who were interviewed is that circumcision works as a “catalyst to speed up a woman's full achievement of her femininity.”⁷⁷ Concerning femininity, in some parts of Africa, the belief system in some FGC communities is one that suggests that the clitoris grows to the size of a male organ, an idea associated with the notion of aesthetics. One reason for the aesthetic viewpoint is that some women in Africa describe their genitalia as ugly and look similar to that of men. It is reported that having genital modification (FGC) not only beautifies the genitalia to look more feminine, but also purifies the female genitalia. The idea of purity, a rationale also linked to the surgery, is that the larger the clitoris the “dirtier and uglier it is. The state of being uncircumcised was termed dirty and had to be washed away.”⁷⁸ It is important to note here that both purity and aesthetics are reasons attributed historically to circumcision. In the historical literature on the FGC, hygienics is associated with the idea of purity, a notion embedded in the early Egyptian culture. Hygienics and purity are named as primary reasons for circumcision of both males and female. While most women agree that the procedure is painful, they embrace circumcision as a rite of passage to being a woman. Circumcision then serves as a way for women to embrace their femininity while beautifying the genitalia, a third reason for circumcision highlighted also by WHO. It is important to mention in this regard young girls, Nevertheless as it relates to the vulnerability of

young girls, the reasons for FGC continue to put young girls in the position of vulnerability and must be protected as articulated by human rights law.

II. Applying the Concept of Vulnerability to FGC via Human Rights Law

The focus of this section will demonstrate how the concept of human vulnerability is applied to women who have experienced FGC, particularly through their ethnicity, gender, liberty, and health status. The UNESCO *Universal Declaration on Bioethics and Human Rights* offers a framework for applying human rights to FGC. [Article 3] includes human dignity as foundational to human rights and cannot be separated from the human condition⁷⁹. As it relates to bioethics, the principle of respect for human dignity holds a place of prominence in the framework.⁸⁰ Human rights also can provide needed guidance on challenging issues related to health that effect people and populations of people globally.⁸¹

Not only does respect for human dignity endow centrality and status, according to Roberto Andorno, respect for human dignity is a requirement and is characterized as the “cardinal principle of legal norms relating to bioethics.”⁸² That is, respect for human dignity is first. Andorno further clarifies that human dignity is not defined by the Declaration in a clear and precise way, but it would be a mistake to see the concept as only a rhetorical strategy.⁸³ Bioethics works from the framework that individuals have an inherent and immeasurable worth. Each human life is regarded as valuable and worthy of respect. Since health care ethics is related to rights and privileges of all human beings, for example the right to life, and the right to choose, then respect for human dignity is paramount.⁸⁴ Human dignity is the foundation on which human rights are based.⁸⁵ Respect for human vulnerability cannot be separated from human dignity.⁸⁶ Michael Kottow writes, “a discussion of vulnerability must necessarily also refer to integrity and dignity, all of which are intertwined in an intimate and inextricable way.”⁸⁷

Regarding human dignity and human rights, the Universal Declaration on Human Rights affirms the dignity of all human beings and recognizes the “inherent dignity of all members of the human family is the foundation of freedom, justice and peace in the world, and is at the heart of most international human rights instruments.”⁸⁸ Especially those instruments banning torture, slavery, inhumane or degrading treatments, and discrimination of sorts.”⁸⁹ However, concerning bioethics, the concept of dignity is not enough to solve the problems raised in the context of health care ethics.⁹⁰ In order for dignity to be applicable to the context of the patient and health care practitioner relationship, the notion of dignity needs substantive and tangible concepts.⁹¹ Some of these concepts include, for instance, ‘informed consent,’ ‘confidentiality,’ and self-determination found in other bioethical frameworks for example, the Georgetown construct of bioethics and the Global bioethics structure, which are framed and articulated by employing the term “rights.”⁹² For example, the principle of autonomy (self determination) as it is articulated by the Declaration [Article 10] affirms that respect for autonomy conveys the liberty of persons to make decisions without prejudice and is based on the fundamental principle of human dignity.⁹³ Women from FGC communities who live in non-FGC contexts are afforded the right then to participate in the cultural life of their community, even outside of the context of the cultural community, that is, to choose FGC as a life plan without prejudice and bias. To affirm the right to involvement [Article 27] inspires the right to participate in the cultural life of a community.⁹⁴ Because of the cultural differences between FGC communities, and non-FGC contexts, particularly the U.S., and US healthcare systems, refugee women who choose FGC surgeries are susceptible to having both their dignity and autonomy threatened. One example of how women can be vulnerable is by having the request for care refused.

Important for the investigation of women under examination, this dissertation not only focuses on the individual dimension of dignity which is the foundation of all rights and freedoms and leads to self-determination, Andorno explains that the category of dignity called the collective sense of human dignity⁹⁵ is just as important. The collective sense goes beyond individual focus on human dignity and refers to the value of humanity as a whole and includes future generations.⁹⁶ The inclusion of future generations is critical to the application of human dignity and vulnerability. Its significance lies in the protection of future generations of women from FGC communities who will choose to undergo FGC. Since human dignity and human rights afford promotion of self-determination, future generations of women are susceptible to their dignity and autonomy being threatened which leaves them open to what Florence Luna describes as a layer of vulnerability.⁹⁷

As it relates to layers of vulnerability, Luna explains that the concept of vulnerability is a concept of relation.⁹⁸ In other words there is a relationship between the person under consideration and the context or life situation. It is this particular context or circumstance that renders a person vulnerable.⁹⁹ An example of the context and the circumstances that render refugee women vulnerable is FGC surgery in a non-FGC context. There are different layers of vulnerability for women who chose FGC in non-FGC communities, specifically health care systems. The use of vulnerability from the layered approach may also prove useful in the context of clinical care for women who choose FGC surgery in an effort to remove and eliminate layers of vulnerability for women who choose FGC in environments where the request for care is not normative.

Human rights law affords the expression of individuals to engage in their specific culture and cultural customs as long as the cultural traditions do not violate the human rights of all

people as guaranteed under the international human rights law.¹⁰⁰ The international human rights system fosters and promotes a wide range of rights¹⁰¹ as investigated earlier in this dissertation. As the international human rights law concerns FGC and vulnerability, and discerns what the care should be for refugee women who are in need of care, consideration must be given to the following categories. They include gender, liberty status, health, and ethnicity.¹⁰²

i. Gender and FGC

Gender is foundational to the FGC debate. The history of circumcision began with the circumcision of men and boys. While the exact date of its beginnings is unknown, historians suspect that FGC predates Christianity and Islam.¹⁰³ The postmark of the FGC into mainstream debates however took place in the early 1960's. Gender played and continues to have a prominent role in the debate. What is interesting, however, in the consideration of gender as it relates to vulnerability and human rights, are the differences made in the observation concerning female and male circumcision. Nevertheless, circumcisions without consent, clearly seems to violate the bodily integrity of both males and females. Yet, when observing male circumcision, there is an inclination not to accept the resemblances of the surgery and the relationship between the two surgeries. Gruenbaum adds, not only is there a tendency to dismiss male circumcision because it seems far less harmful than FGC, FGC is seen as a "different phenomenon despite the strong similarities in reasons given for performing both male and female circumcision."¹⁰⁴ Further, Gruenbaum explains that male circumcision is deemed a Jewish tradition paralleling the custom of entering a Jewish male child into the covenant of Abraham on the one hand and on the other the crippling and painful mutilation practiced by societies in which women are sexually and socially oppressed.¹⁰⁵ One practice is a sacred rite, the other a "morally reprehensible behavior."¹⁰⁶

As it relates to vulnerability and international human rights, male circumcision and FGC are a violation of the right to freedom, bodily integrity, and autonomy if done involuntarily and without consent. The violation of these rights, according to the Declaration, renders men, and women, girls and boys vulnerable when placed in a situation where they cannot choose. For both genders undergoing circumcision without consent threatens dignity, self-determination, and bodily integrity, make them vulnerable and in need of protection. It is noteworthy that men are not a category on lists to denote vulnerability. In an analysis by Morawa on categories and criterion, the group in which boys are assigned is age, which then allows them to meet the vulnerability criterion.

Relating to the women, the international human rights law framework designates women as a vulnerable population. As mentioned in the earlier section on women, there are scholars who are against using gender as a category of women as vulnerable populations.¹⁰⁷ Rendering women for the sake of gender does not make women vulnerable. Most lists, however, designate women as a vulnerable population. What is troubling about classifications and groups, especially as it relates to refugee women who choose FGC surgery in a non-FGC context, is that there is no consideration given to eradicating the vulnerability. Another concern with classification or categories is the potential to foster discrimination against certain groups. Prejudice and bias promotes discrimination, which serves a barrier to health care, particularly in environments where there is a lack of cultural competency and cultural sensitivity. According to international human rights law, members of minority groups, for instance- racial, ethnic, and religious groups are entitled to special protection to be free from discrimination. To discriminate against individuals, and in particular refugee women who choose FGC, or other groups of people (who are in need of health care) is an act contrary to respect for human dignity and is deemed

repugnant to many principles in the Declaration.¹⁰⁸ The act of discrimination is in conflict with the promotion of respect for human dignity and human rights of all people and in fact is “the primary reason for the document.”¹⁰⁹ It is in light of discrimination that protection is needed. The most profound justification for human rights is human dignity and is the fundamental reason behind the prohibition of discriminatory practices.¹¹⁰ It is important to mention that discrimination and non-stigmatization is one of global bioethics principles outlined in the *Universal Declaration on Bioethics and Human Rights* [Article 11]¹¹¹. While discrimination and non-stigmatization are not areas of exploration in this dissertation, the principles are unearthed here and warrant further investigation with respect to women who choose FGC and the vulnerability.

Carol Levine argues that the use of vulnerability fosters stereotyping.¹¹² Labeling women as vulnerable, according to Florence Luna, suggests that the assignment of vulnerability is a permanent condition that persists without resolution.¹¹³ As vulnerability relates to care, permanency is not in line with the goal of care. Since the goal of medical care is to improve the quality of life for patients by facilitating positive outcomes, there is a need for the practical application of respect for vulnerability via the human rights framework. Using this framework will assist to avoid the permanency of a vulnerable situation. In the practical application of vulnerability via human rights, the health professional is responding to vulnerability in a way that affirms the inherent dignity of the individual thus paying attention to conditions that would not support the patient to thrive. An additional reason to work with vulnerability via the human dignity construct is the principle of human dignity holds a prominent place in the Declaration and in intergovernmental instruments concerned with bioethics.¹¹⁴ Andorno refers to the principle of human dignity as “the shaping principle.”¹¹⁵ Therefore the Declaration assigns the

first place to the principle of human dignity, human rights, and fundamental freedoms [Article 3.1] in which all other principles are constructed. Therefore, because of the weightiness of the principle of human dignity when considering what the care should be for refugee women who choose FGC, vulnerability must be responded to in light of respect for human dignity, human rights, and fundamental freedoms.

A positive outcome to consider is to eliminate the vulnerability, a theme explained by Luna.¹¹⁶ An example of eliminating the vulnerability is observing women and FGC. For instance, while gender identity and gender definition are not at time highlighted to the degree of strong consideration, regarding reasons for FGC, gender identity is one reason for FGC surgery. What is important here concerning vulnerability and human rights law is that for women considering FGC, due to gender definition, gender identity becomes what Luna refers to as a particular layer of vulnerability. The layer identified is the situation or the circumstance that renders women who choose, FGC surgery vulnerable.¹¹⁷ Human rights law affords refugee women choosing FGC surgeries, bodily integrity, autonomy and a right to participate in their culture. In other words, women who make this decision are free to do so.

ii. Liberty Status and FGC

Liberty status is one of the criteria to meet the terms of vulnerability. Alexander H. E. Morawa explains that while the list offered on criteria for vulnerability is not exhaustive, liberty status is a general category that characterizes the criteria concerning how the vulnerable can be separated out.¹¹⁸ Morawa names refugees as vulnerable. Liberty status refers to the right and the power of an individual to act, think, and believe or be able express oneself in the way he or she chooses. In addition to the right to think and believe as wished, liberty is the condition of being physically and legally free. The refugee status in some cases impedes the notion of liberty.

In the set of circumstances framing refugees and specifically refugee women, because of their refugee status, they are under terrifying threat and are susceptible to arduous injury if they are not in a safe environment, such as the U.S. However, specifically for the refugee women observed in this dissertation, the threat is related to health care. That is, the threat of not being able to make autonomous decisions about health decisions, namely to undergo FGC surgery without interference in a harmful or adverse way. The interference in this circumstance is the refusal to honor the wishes of the patient, which threatens the ability to choose.

Related to the context of women refugees, Carol Levine's definition of vulnerability is useful. What makes her definition of vulnerability useful, especially as the concept relates to FGC who choose FGC is Levine, includes in her definition of vulnerability the concept of incapability,¹¹⁹ a notion used in health care ethics to describe an individual's inability to make medical decisions.¹²⁰ An inability and incapability to exert agency renders one vulnerable and susceptible to injury and harm. Levin further discusses that vulnerability is associated with an individual's ability to protect his or her own interests and explains "incapability of protecting one's interest is because individuals have insufficient power, intellect, education, resources, strength, or other needs that attribute to protecting one's own interest."¹²¹ Levine's description of vulnerability accurately describes the circumstance of refugee women in a non- FGC environment with regard to their liberty status. For women in the environmental context where FGC is countercultural, perhaps the education, namely health care literacy makes women choosing FGC surgery vulnerable. That is, refugee women may not know they have the right to self-determination. This lack of knowledge may serve as a barrier to protecting their self-interest, liberty and health status.

iii. Health Status and FGC

Health status is another criteria needed to meet the terms of vulnerability. Alexander H. E. Morawa explains, one of the fiercest topics in the debate concerning FGC is the discussion on alleged health consequences and potential health risks caused by FGC. The health consequences associated with the practice are at the heart of the debate and present serious ethical dilemmas and queries. There are supposed physical and psychological complications associated with FGC. Concerning the health consequences, there are both short term and long-term complications. It is important to note here that some of the research on FGC does not reflect which type of circumcision is associated with specific health risks and implications rather the literature reflects that there is “possible” immediate complications for all types of circumcision.¹²²

The alleged short-term consequences that are linked to the FGC include severe pain, bleeding, and shock from the intense pain. Other assumed and potential negative health implications are risks of infection such as HIV/AIDS, and hepatitis B and C. The presumed long-term complications are associated more often with Type III, infibulation.¹²³ These suspected long-term outcomes include difficulty with menstrual flow and urination, both of which can cause infection. Untreated urinary tract infections can “ascend to the kidneys and bladder, potentially causes renal failure septicemia which can lead to death.”¹²⁴ In some cases, Type III, or infibulation, can cause damage to the sexual organs. Other complications attributed to the surgery and particularly Type III are obstetrical complications, infertility, and cysts, among other things.¹²⁵ Many of the health risks that are associated with the surgeries result from unhygienic circumstances. One example of the unhygienic conditions described in the scholarship, is the use of dirty instruments. Often the unsterilized instruments are knives, razor blades, scissors, thorns, and pieces of glass. Some of the scholarship on health risks especially characterizes “un-

sterilized” to mean that instruments are used over and over again, without sterilization, a reason attributed to the high rate infection.¹²⁶ Other reasons associated with the health risks are the dismal lack of medical treatment as well as the substandard medical treatment and care available to women after the surgery is performed. Health professionals are often unfamiliar and do not have the knowledge necessary to treat and care for women who undergo the surgery. The health professional’s unfamiliarity and lack of knowledge concerning FGC can also render women vulnerable. In other words, the unintended incompetency of the health practitioner makes for a situation that causes women experiencing FGC undue susceptibility to possible harm. It is the moral notion of competence that must be present when considering what the care for women experiencing FGC should be, a theme investigated further in Chapter 7 of this dissertation.

It is critical to note that the literature on the health consequences of FGC is abundant, and some scholars argue that it is one-sided and unbalanced, as there are opposing points of view. The conflicting viewpoint of the literature concerning health consequences is that the volume of literature on FGC and the health consequences is a dramatization of western views regarding FGC that frames the health consequences in a dismal light. This is not to say that women undergoing the procedure have not experienced negative health consequences, as is the risk with all surgeries. The potential outcomes must be examined in a larger context that includes an ethical analysis of care for women who undergo the surgeries. Nevertheless, it is the circumstances related to health that makes women considering FGC vulnerable. Other matters related to health status described in the scholarship refer specifically to emotional, psychological, and spiritual harm. For some women, the effects of the psychological trauma include a breach of trust and confidence in family and community.¹²⁷ Other women, depending on their age, have a different experience.

When exploring the health status of women who experience FGC surgeries, not all women share the same experiences. Ylva Hernlund explains, concerning psychological trauma, that the psychological impact and well being of women who have undergone FGC requires more research.¹²⁸ It is important to note that the some of FGC literature that describes the psychological and the emotional effects of FGC are associated largely with young girls and not with women who whose life plan is to have the surgery. Regarding other situations related to health status mentioned above, there is little research found in the scholarship on the emotional, and spiritual harms of FGC to women experiencing it. The highlighted health effects are namely the potential physical health consequences of FGC. Under international human rights law health, individuals are entitled to enjoy the “highest attainable standard of physical and mental health.”¹²⁹ For refugee women who choose or who have experienced FGC surgery, health status is a particular situation in which vulnerability is rendered.¹³⁰ However, if the surgery is done in a way that is medicalized the refugee woman choosing FGC is not vulnerable as it relates to the relation of her health status.

iv. Ethnicity and FGC

A distinguishing factor that is related to refugee women, vulnerability and FGC is the idea of ethnicity. Cultural Diversity, Chapter 5 of this dissertation, unearths in systematic and full detail how ethnicity is intimately linked to women who will experience FGC. The chapter makes the connection of how ethnicity is closely associated to cultural diversity. For the purposes of this section, it is important to mention that ethnicity is one criterion for the assignment of vulnerability. Ethnicity is defined as a group or population of people whose members identify with each other and share cultural traits and shared history. The feature of ethnicity is critical to the entire discussion on FGC and especially to vulnerability and human rights, as the focus on

the women in question are from different ethnic groups. According to Morawa, ethnicity is one of the criteria that help meet the terms of vulnerability. He further illustrates that ethnicity is at times co-mingled with residency status, minorities and indigenous people, and rural populations¹³¹ These minority groups include racial, ethnic, religious, or linguistic aspects, and are entitled to special protection to enable them to maintain their culture free from discrimination. [Article 2] further explains, “persons belonging to ethnic groups...have the right to enjoy their own culture.”¹³² The Declaration, in addition, articulates that the exercise of the rights described in [Article 2] “shall not prejudice the enjoyment by all person of universally recognized human rights and fundamental freedoms [Article 8(2)].”¹³³

Individual cultures that have characteristics that distinguish themselves as spiritual, material, intellectual, or emotional features are what make up culture.¹³⁴ These aspects of individual cultures also embrace and embody “lifestyles, ways of living together, value systems, traditions, and beliefs,”¹³⁵ all features of FGC communities. Human rights are rights that apply to all people. Furthermore the Declaration notes that, since human rights are universal, they “guarantee the particular expression of individual cultures.”¹³⁶ As it relates to the vulnerability of people who are of a different ethnicity, care demonstrated includes protection of the right to practice traditional customs.

III. Applying Human Vulnerability and Voluntariness

A. Voluntariness and vulnerability

The principle of vulnerability is related to that of voluntariness. In exploring the relationship between vulnerability and voluntariness three concepts present relative to refugee women and FGC. The first is the current involuntary nature of the practice and the second is the voluntary decision made by women to undergo FGC. The third concept used is social vulnerability. An

exploration of social vulnerability helps to determine how to apply vulnerability to refugee women who undergo the surgery either involuntarily or voluntarily. The topic of human vulnerability is connected to autonomy since an autonomous individual can choose or volunteer for what happens to her body.

Refugee women are women who now live in a different cultural context that affords choice, not only for themselves, but also for their daughters. These women voluntarily undergo the procedure. Applying vulnerability to women who voluntarily choose to undergo the surgery necessitates further study. Investigating the vulnerability of future generations also requires examination. Completing the analysis of vulnerability will help to determine the vulnerability of these groups of women and assist in establishing what care should be. The concept of voluntariness has become an important feature in bioethics¹³⁷ and is one basic dimension of the concept of autonomy. It is employed as the second element of informed consent and third of three conditions of autonomous action.¹³⁸ Voluntariness as it relates to the individual receiving care must be in a position to have the power to choose without outside control or coercion. Additionally, voluntariness is the ability of the individual to determine the desired intention without being under the controlling interference of another person, illness, or disorder that can diminish voluntariness. An example of diminished voluntariness is a person who is mentally ill and unable to volunteer. Mental illness can interrupt an individual from autonomous choice and intention.

Voluntariness is a concept salient to the notion of care, particularly when applying the concept to the autonomous decision of those whose healthcare decisions and intentions may not be a normative one. The idea of voluntariness is particularly relevant to refugee women who live in cultures where FGC is not part of the established norm and who will voluntarily undergo the

procedure. Chapter one of this dissertation established that for women to undergo FGC surgery involuntarily is ethically unacceptable. On the other hand, however, the scholarship on FGC makes clear that there are women who embrace the surgery and who voluntarily undergo the medical intervention.¹³⁹ Since the surgery is historically a cultural tradition that is transmitted from one generation to another, one ethnic group and community to another, it is probable that there will be future generations of women who will also embrace their cultural tradition and will voluntarily undergo the surgery. The concept of voluntariness is useful in this context of care.

The notion of voluntariness describes acting in accord with one's intention. When employed by an autonomous individual, the person has a desire for a specific action and is compelled to do so without being swayed, or under authority or domination of another.¹⁴⁰ It is important to mention, although not addressed in this dissertation that the mental or emotional condition is at times a concern and must be taken into consideration. One of the queries raised when considering the notion of voluntariness concerns the intentions of the individuals influenced by outside factors. For instance, are the intentions or life plans of an individual influenced by one's values and beliefs or are they influenced by the interdependence of community and culture in which we live?

In the previous section of this chapter, the notion of influence was examined, and it was determined that there are factors that influence an individual's autonomous intention. These factors include the social determinants such as gender, ethnicity, and the values and beliefs of the community in which an individual belongs. With respect to voluntariness, being influenced by non-coercive values and actions does not mean that the life plan or the intention of the individual is not an autonomous one. The investigation on influence further determined that the decision of the individual should not diminish and that care must be taken to respect the autonomous wishes

of the individual. Furthermore, due to the nature of the social-self and the social-identity of individuals, it is impossible for there not to be a certain measure of influence.

Nevertheless, it is crucial to note, that according to the scholarship on the voluntariness in the bioethics literature, influences are both negative and/or positive.¹⁴¹ Negative influences are associated with coercion, also a subject often reflected in the discourse on FGC. Coercion is most often associated with a threat. It is at this juncture that the influence becomes a negative one. Importantly, the idea of coercion exists only when the “intended and credible threat displaces a person’s self-directed course of action.”¹⁴² When the displacement of an individual’s intention occurs the decision is no longer an autonomous one.

This understanding of negative influences and coercion is particularly useful when it is associated with the autonomous choices of individuals especially as it relates to ethical decision making about one's healthcare, namely FGC. When the autonomous decision is made that is not normative, meaning the decision does not attend to the standards of the established norm, the idea of influence is assumed to be a negative one. An example is the controlling influences of the healthcare practitioner who is providing care for a refugee woman who chooses to undergo FGC. Not only is there an opportunity for disagreement between the patient and the healthcare professional, there is also a chance for the health practitioner to refuse to provide care. The refusal becomes a controlling influence that can thwart the voluntary intention of the woman receiving care. The notion of controlling influences is a theme that draws robust debate in the scholarship on FGC. However a noteworthy observation is made in exploring the scholarship on FGC. The focal point of controlling influences is often toward the community ethos in which women who have experienced FGC live, rather than negative influence of the practitioner.

Since the notion of voluntariness is associated with autonomy and providing care, the health practitioner must take precautions not to become the actor in the controlling influence. To facilitate voluntariness, positive influences are employed, namely the type of treatment and actions that foster autonomous decision making. Therefore, when providing care the healthcare professional must be careful not to impose on one's self directed intention. As it relates to future generations of young women who will have intentions to undergo FGC surgery the idea of voluntariness is critical when applying it to care of women who will choose. Women who voluntarily undergo FGC, that is, women who make an autonomous decision to choose remain susceptible to vulnerability. Illustrated by Ganguli-Mitra and Biller-Andorno, vulnerability is inherent to various clinical contexts.¹⁴³ What is of paramount importance is the vulnerability of women who choose to undergo FGC, or who have already experienced the surgery, are in need of care, and they have inadequate or no access to health care.¹⁴⁴ Not having access to healthcare or having substandard healthcare is commonplace for immigrants, certain marginalized groups, and ethnic minorities.¹⁴⁵ While healthcare is intimately linked to patient preferences, having no access or inadequate access deems women experiencing FGC vulnerable.

As it involves healthcare, inadequate and substandard care can be deemed in two ways, concerning FGC, vulnerability, and women. One-way the inefficiencies of care is realized is the lack of cultural competence, education and sensitivity regarding FGC. The lack of cultural aptitude includes, but are not limited too both the emic and etic perspectives of the women and the cultural context in which FGC occupies. In addition, education about the practice is critical and is also absent. What is also necessary to the idea of voluntariness and vulnerability is the moral precept of responsiveness.¹⁴⁶ Responsiveness requires that health care practitioners remain vigilant to the possibilities where vulnerabilities might arise. Another way that inadequacies and

substandard care can be understood is contextual. Context has to do with the conditions in which FGC surgeries are performed. An example of conditions is the unsanitary condition of the instruments used and the environmental circumstances. Because women from FGC communities embrace their cultural traditions, namely FGC, the decision to undergo FGC surgery is meaningful and important, and therefore the practice is imminent. As it further relates to conditions, some of the research regarding FGC in the U.S. reports that FGC is affecting more women in the U.S. than once predicted.¹⁴⁷ Further, women from FGC communities are undergoing the surgery here in the U.S. often underground, perhaps by medically untrained individuals and environments that are not conducive to perform medical surgery. Living in a cultural context that is a non-FGC one with the desire and plan to undergo the surgery, whether it is in the healthcare system or underground, leaves women who voluntarily choose FGC open to harm that may otherwise be negated if the intervention was done within the confines of the healthcare system.

B. Involuntariness and Vulnerability

A major feature of FGC and the human rights debate is the involuntary status in which FGC is often performed. In the investigation of FGC, presented in Chapter 4, it is argued that women who undergo FGC involuntarily are women who live in a cultural context in which they are accustomed to FGC. There are women who experienced the surgery as girls and did so involuntarily and without giving consent. The involuntary designation, that is, women who are exposed to the involuntary nature in which FGC is currently practiced, is ethically unacceptable and leaves women open to injury. According to the Declaration, which articulates those who are vulnerable are individuals, particularly women, whose autonomy, dignity, or integrity are capable of being threatened. Articulated by the Barcelona Declaration it is the danger of losing

self-determination that renders an individual vulnerable. Additionally, respect for autonomy includes expressing appreciation for the right of individuals to embrace views, intentions, to make decisions and to live based on their values and belief. Respect for autonomy then is to respect the individual autonomy of others and to acknowledge their right to embrace views, beliefs, and values of their choosing. Further, employing respect for autonomy means that respect is given to the right of individuals to make decisions, life plans, and takes action based on their beliefs and values, even when there is disagreement between the beliefs and practices of a culture.

Therefore, generally understood autonomy or individual autonomy refers to the ability to be one's own person, to live one's life according to the values, views, and beliefs embraced by the individual, without manipulative, oppressive, or external forces. In addition, autonomy is considered to be a principle derived from and based on a more fundamental principle, human dignity. Since human dignity is a fundamental principle, autonomy finds its justification and validation for its use in the human dignity and human rights framework.¹⁴⁸ A denial of the self-determination that fosters involuntary action, namely FGC surgeries against a woman's will, is at the very heart of vulnerability. It is noteworthy, however, to mention here that vulnerability is not only associated with the autonomous right of the individual, it is at times a characteristic of the individual and the context in which the individual is situated.¹⁴⁹ Concerning human rights and human dignity, because human rights are articulated as a principle that shapes how care is employed, the involuntary status of women having FGC against their will deems them vulnerable. The reason for the vulnerability assignment for women who do not choose is the lack of voluntariness.¹⁵⁰

The lack of voluntariness related to FGC is what is referred to in the literature as the

grossest form of physical harm.¹⁵¹ In addition, it is the involuntarily nature of FGC that is regarded as torture, gender violence, and a violation of the human rights for women and girls who are forced to undergo the cultural traditional practice.¹⁵² The involuntary position of women who do not choose FGC surgery, namely when the surgery is performed without consent, is unethical. The unethical designation is clear, as the forced FGC is abuse of ones right to freedom and right to choose. In light of forced FGC, or as it is referred to in the literature, “forced excision,”¹⁵³ places women in harms way and leaves them susceptible to vulnerability and in a position where there is lack of autonomy. It is the involuntary position of women in FGC communities who decide against FGC and are forced to do it regardless of their wishes that make women vulnerable. However, it is this particular group of women rather than all women who are vulnerable.

While there are a host of rights violations as it relates to the involuntary position of refugee women who choose not to undergo FGC surgery, and are forced against their wishes it is here that the matter of gender oppression is realized. Certainly women who involuntarily undergo FGC are powerless and therefore vulnerable.¹⁵⁴ It is interesting to note Ruth Macklin argues, women who undergo FGC against their will are not powerless in a way where more powerful individuals are benefiting from actions performed on the individuals who have less power, for example research subjects, although the issue of power is often part of the FGC discourse. Macklin further explains that no one benefits from the alleged harms inflicted on women who do not choose.¹⁵⁵ The powerlessness is realized in the act of taking away the agency of women to exercise her self-determination on her own behalf. Taking away the autonomous choice makes individuals, particularly women, powerless and vulnerable and in need of care, that is protection. Intriguingly, however, refugee women who experience FGC are often part of a larger social

group. Therefore refugee women, in non-FGC communities have layers of vulnerability, not only individual vulnerability but also in the context of social vulnerability.

C. Social Vulnerability

Social vulnerability is a concept used most often in research ethics. Social vulnerability in the health care and research contexts has to do with the participants who are part of the social group that is undervalued.¹⁵⁶ That is, those specific groups for which society has insufficient regard or values below their worth as human beings. For example refugee women who choose FGC surgery and are in need of care, some minorities groups, mentally ill etc. Social vulnerability also refers to the inability of communities and societies to survive the adverse effects and influences of stressors to which they are exposed, for example war, natural disasters, etc. Social vulnerability suggests, in addition, the resilience of communities when confronted by external stresses on human health and stressors such as natural or human-caused disasters.¹⁵⁷ More specifically social vulnerability is present when there are impacts due in part to characteristics inherent in the social interactions and systems of cultural values, namely FGC. According to Kipnis, social vulnerability is a function of the social perception of certain types of groups, which includes stereotyping and can lead to discrimination. This kind of negative perception devalues the members of the particular group and includes the interests, values, or their contributions to society.¹⁵⁸ A more comprehensive examination of the strong social characteristics, i.e., ethnicity, gender, cultural values, and social status associated with FGC is observed in Chapter 5 of this dissertation. What is important to note here is how social vulnerability as it is connected to health care refers to groups of people who are regarded to have diminished worth and therefore deemed vulnerable.

Concerning vulnerability, Mitra and Andorno argue, regarding undervalued social groups,

that the designation of vulnerability is not intrinsic to the individual, rather it is the overlay of characteristics of the person, and the environment in which she find herself.¹⁵⁹ Luna proposes a similar approach to vulnerability as it relates to the specific situation and circumstance in which a person is involved. She refers to vulnerability as a principle that is observed in relation to a situational context where there are layers of vulnerability.¹⁶⁰ It is the “ particular situation that renders someone vulnerable.”¹⁶¹

The traditional practice of FGC is firmly established within the context of culture and ethnicity of social groups; both are intimately linked to what may constitute as an undervalued social group. Since the notion of an undervalued social group is subjective in nature, for the work of this dissertation undervalued is to mean insufficient regard for other. While diminishing the value and worth of other can be characterized as an abuse toward other and an infringement of the human dignity and human rights framework, the lack of regard is associated with the individual characteristics of other address by Luna.¹⁶² Refugee women who live in a non-FGC context bring with them their values and theirs beliefs and are different that the US value and cultural ethos.

Luna refers to vulnerability as a concept that is acquired. In addition, Luna describes that there are layers of vulnerability¹⁶³. She also argues that vulnerability is not constant, that once the reason for the vulnerability is addressed, the patient (or research subject) is no longer vulnerable. However, if the characteristics of the individual are part of the make up of the person in question, for example refugee women whose choice to honor their cultural tradition, values, beliefs, namely their “own characteristics” then the rendered vulnerability cannot be lifted. An example of vulnerability that is not persistent is a refugee woman who now lives in a non-FGC cultural context and voluntarily undergoes FGC surgery; once the situation is resolved the woman is no

longer vulnerable.¹⁶⁴

The acquired layer of vulnerability rendered changes according to Luna if the woman's situation changes. Perhaps it is one layer of vulnerability that is removed because, according to Kipnis, it is belonging to an undervalued social group that renders a person vulnerable.¹⁶⁵ In other words, if a group of people who are diminished in value because they are part of a particular group, for instance, women who choose to undergo FGC in non-FGC contexts, the layer of vulnerability seems to be one that cannot dissipate. It is part of the characteristic of the person. Perhaps it is not the ethnicity or cultural values and beliefs in which they receive insufficient regard, it is the discrimination that makes the vulnerable and susceptible open to harm and abuse. It is critical to note here that in his approach to vulnerability Kipnis is specifically talking about the context of research. Even so, whether it is the relationship with the participant and the investigator, or the patient and the healthcare practitioner vulnerability, is a noteworthy consideration.

One example of the harm employed is discrimination that is realized in the patient/healthcare practitioner relationship when the goal is not quality of life for the patient via her autonomous choice. As mentioned earlier in this chapter, discrimination is a violation of human dignity and human rights therefore the principle of vulnerability must be rendered. In thinking about what the care should be for this particular group of women, vulnerability is a useful concept. Concerning vulnerability, for women who choose to undergo FGC, the principle of vulnerability makes clear the need for a watchful eye for the different kinds of vulnerability¹⁶⁶ and the obligation to protect.

IV. Applying Vulnerability and Care to FGC

A. A responsibility to protect

In the discourse on human vulnerability, the concept of protection is a predominant theme. In fact, as demonstrated in the Barcelona Declaration, vulnerability is the object of a moral principle requiring care for the vulnerable. As vulnerability relates to care for those who are vulnerable one way to realized care is through the responsiveness. The examination in this section will not only investigate the concept of protection and vulnerability, but also explore whether the idea of protection can be realized in lessening the harm that is associated with FGC in its current context, which is ethically problematic. Additionally, scholars have argued that the idea of protection is not only for “all people living today, but it refers a chain of generations who will collectively form one community whether living now or in the future.”¹⁶⁷ Future generations, particularly women who will choose to undergo FGC, are a feature of this dissertation. The notion of protection and vulnerability has implications for the model of care for this specific population and will be further examined in Chapter 7.

The concept of vulnerability asks us to respond. In responding to vulnerability, the action carried is to protect. Michael Kottow explains that human vulnerability “requires active protection from negative forces and prevention of harm.”¹⁶⁸ Some scholars argue that responsiveness suggests obligation and responsibility. While the notions of obligation, responsiveness, and responsibility are not the primary focus of this dissertation, the literature demonstrates that responsiveness is a compelling concept, in constructing approaches adaptable universally which respond to vulnerable populations. Robert Goodin argues there is a social responsibility to respond to those who are vulnerable.¹⁶⁹ To advance the idea of responsibility and respond to those who are vulnerable, Daniel Engster writes, “the moral obligation to meet

others' claims for caring thus rests upon the intuitive idea that human life and basic well being are valuable and should be supported.

Our unavoidable dependency combined with the value we place on our lives thus commits us to caring for others in need.”¹⁷⁰ Related to the inescapable dependency of human beings is an additional understanding of responsibility and vulnerability. Hen ten Have explains, there is an “ethical responsibility between human beings.”¹⁷¹ The responsibility is due to our fundamental interconnectedness as human beings.¹⁷² That is, the moral obligation to take action towards other is not from a place of rationality or reasonableness, rather action is from a place of our common humanity.¹⁷³ Conversely, Joan Tronto cautions that vulnerability has serious implications, most specifically, that vulnerability contradicts the illusion that we always, at all times have self-determination and equality, an idea that warrants further exploration as applied to vulnerable populations. To ignore the issues that accompany autonomy, reliance, and unequal power distribution is disconcerting ¹⁷⁴ particularly as it relates to persons who are without basic needs for survival and therefore, are suffering.

Robert Goodin assists in the effort of re-conceptualizing vulnerability by making clear that there is a moral responsibility to protect those who are “susceptible to injury or woundedness either figuratively or literally”¹⁷⁵ The concept of protection is a broad term and encompasses diverse meaning depending upon the context in which the word is used. In its most literal sense protection is a term employed to mean a person or thing that prevents someone or something from suffering harm or injury. Protection is a legal term and refers to the legal or other formal measures intended to preserve civil liberties, and rights. It includes a document guaranteeing immunity from harm to the person specified in it. Concerning human rights, we have determined that protection, a right to protection, is fundamental to human rights. This protection is facilitated

by the state for the security of all people. While the US constitution guarantees protection, Helton notes that there are several treaties that extend protection to refugees, including those seeking asylum. For example, the interest for the right to protection is clearly reflected in the Charter of the United Nations and the Universal Declaration of Human Rights.¹⁷⁶ There is a specific document however on the protection of refugee women. According to the UNHCR's Guidelines On the Protection of Refugee Women, protection for refugee women is at the heart of the responsibility that the international community bears towards refugees.¹⁷⁷ The document acknowledges that most of the world's refugees are women and children and further explains that female refugees are particularly vulnerable to physical violence, sexual abuse, and discrimination.”¹⁷⁸

The concentration of this dissertation is on refugee women who are living in the U.S., specifically in need of care, concerning the choice to undergo FGC surgery. Therefore, the emphasis is on discrimination as it relates to protection, a theme illuminated throughout this chapter. What is important about the guidelines offered in the UNHCR is refugee women are deemed a group who are especially deprived, rendering them vulnerable to actions that leave them susceptible to situations and the contextual features that can cause a nonphysical form of injury, namely discrimination in a health care environment. It is important to note here that all human beings are vulnerable to discrimination. However those who have a different ethnicity, the elderly, those who are disabled or gay are at greater risk.¹⁷⁹ Therefore, the specific action that threatens refugee women who choose FGC surgery, who are in need of care, is the protection that safeguards their right to choose without interference. According to the Guidelines on the Protection of Refugee Women, women who are refugees are victims or are potential victims of human rights abuses,¹⁸⁰ namely their autonomy and dignity are in danger of being

abused. What I mean by *abused* is refugee women who choose FGC surgery in a non FGC environment may be manipulated into making a different decision or denied the care that represents the patient's quality of life decision based on her personal autonomy, verses the preferences of the observer, i.e., the healthcare practitioner. Protection, in this sense, is to preserve and strengthen the right to choose. Because FGC is associated with culture, religious beliefs, and traditions, it is noteworthy to emphasize that the Universal Declaration of Human Rights affords the right of people to participate in their culture, as discussed in Chapter 5 on Cultural Diversity. That is, the right to culture is a human right. In addition to the right to participate in culture, the right to self-determination, there is a right to be protected against discrimination.

At the core of protection is responsibility. Described by the *Universal Declaration on Bioethics and Human Rights* [Article 8] the Declaration addresses the principle of human vulnerability and human integrity and further explains that individuals and groups of special vulnerability should be protected. That is, there is a responsibility to protect. Protection as related to health care ethics is realized in two ways; it includes research ethics and the clinical care. In the context of this dissertation clinical care is emphasized. Protection is not defining the needs of those who are deemed vulnerable.¹⁸¹ Rather, protection is employing safeguards necessary to meet the requirements of ethical conduct.¹⁸² Ethical conduct has to do with the framework of bioethics, which serves as an ethical construct in which the actions and behaviors of health practitioner are guided. The Georgetown bioethical framework includes autonomy, beneficence, non-maleficence, and justice. On the other hand, the global bioethical framework is made fifteen principles, which include the principle of vulnerability and integrity. Therefore, the ethical conduct is not only a guide rather it includes a demonstration and reflection of the principles in

the relationship between the patient, particularly women who choose FGC and the health practitioner.

Vulnerability requires care. Vulnerability is the intention, if you will, of rendering particular individuals and groups of people vulnerable.¹⁸³ The designation of the principle of vulnerability makes clear that there is a moral obligation to act. Vulnerability signals that there is an opportunity for the human rights, dignity, and integrity of individuals and populations of people to be thwarted. The moral obligation to act can be characterized as responsiveness. Joan Tronto describes responsiveness as a moral quality that arises out of care.¹⁸⁴ Not only does responsiveness occur as a result of care, Tronto further explains that, by its very character, care involves responding to situations and circumstances of vulnerability.¹⁸⁵ As it relates to vulnerability and protection, an understanding of the layered approach argued by Luna, helps to call attention to the importance of observing the relationship between specific groups of people and particular individuals, and certain situations and contexts.¹⁸⁶ For example, care involves having an awareness and watchful eye on particular groups of people, namely refugee women who choose FGC in non-FGC contexts, specifically non-FGC health care contexts where the competency about FGC is insufficient. Protection for those who are rendered vulnerable is realized in the context of care.

B. Human Vulnerability and Care

The principle of respect for vulnerability is an important framework in constructing a model of care for refugee women who choose to undergo FGC and are in need of care.

A common thread in the dialogue on human vulnerability is the susceptibility to injury and harm and the need for protection. Harm and injury can be physical and nonphysical. Injury can include mental, emotional, and spiritual harm which can render individuals vulnerable and in need of

care. Requiring care as it is related to refugee women who will choose to undergo FGC surgery goes beyond the confines of physical care in the healthcare enterprise. This is not to say that FGC is not associated with health consequences, and that those who experience the surgery are not in need of care- they are. However, as it relates to the specific situations associated with human beings, which some argue makes every person vulnerable,¹⁸⁷ there are situations that render individuals in danger of having their autonomy threatened. Another condition that renders women vulnerable is discrimination. Since vulnerability can present in different ways, the scope of care is specific to the situation that renders individuals vulnerable, that is refugee women who are living in non-FGC environment and choose to undergo the surgery and are in need of care. Care for this specific group of women is found within the confines of protection for their situation, namely to safeguard against the threat of discrimination, and the danger of their autonomy and dignity unrealized. Limited capacity to understand their right to self-determination, specifically in the context of healthcare decisions is also a consideration.

The vulnerability of the other imposes certain moral obligations on us, according to Ganguli-Mitra and Biller-Andorno, that is, a moral obligation to protect the vulnerable other.¹⁸⁸ However, before there is a moral duty to protect human vulnerability must be respected.¹⁸⁹ That is, to consider the fragility of the human condition. Similarly, the underpinnings of the ethics of care framework, examined more fully in Chapter 7, is established on the grounds that there is compelling moral significance of attending to and meeting the need of others in which we take responsibility,¹⁹⁰ namely the health care practitioner providing care for women who undergo FGC surgery. It is in the context of care that the vulnerabilities and needs of the patient are realized and attended too. Since care is a relationship between the carer and the cared for, it is in the relationship that the principle of vulnerability is applied. It has been established that

responsiveness is connected to care. In the relationship between the health practitioner and the patient, responsiveness necessitates that the health professional is attentive and aware of the possibilities for abuse that arise with those who are vulnerable. In fact, it is the obligation of the health care practitioner to do so. The development of a capacity for responsiveness by the health care professional is an important moral quality in caring.¹⁹¹ Its importance lies in understanding the needs of other, protecting the autonomy and dignity of women who choose to undergo FGC surgery, and the attentiveness of the health practitioner to be aware of potential abuses that arise in caring for specific vulnerable peoples and populations.

In connecting care to the principle of vulnerability, the concept of attentiveness is necessary if care is to be realized. According to Tronto, attentiveness is one of the ethical elements of care.¹⁹² While the ethics of care is more fully examined in Chapter 7, it is important to mention here as attentiveness presupposes responsiveness.¹⁹³ It is noteworthy to mention because in caring for the vulnerable, particularly women who undergo FGC surgery, an attentiveness and awareness to their contextual features can produce opportunities for vulnerability. That is, conditions where women who choose FGC surgery's autonomy or dignity are in danger of being jeopardized, or discriminated against because of their ethnicity. By no means are these the only places of vulnerability for women experiencing FGC. For example, Carol Levine illustrates that some persons may be incapable of protecting their own interests because they may have insufficient education or resources among attributes that could be barriers to them protecting their own interests.¹⁹⁴ Certainly, a refugee woman living in a different cultural environment may not have health care literacy that allows her to protect her health care interests, namely the right to choose her own direction for care.

Attentiveness allows for the health practitioner to be concerned with the needs of the

patient. According to Tronto, if the health care professional is not attentive, that is, ignoring the needs of the patient, then, the practice is one of an unethical nature.¹⁹⁵

In other words, there are ethical implications of caring for those who are vulnerable, particularly as it relates to human rights and women who choose to undergo FGC in a context where this choice is not normative. What I mean by ethical implications is that the results of care are not beneficial to the patient, and the care given should not be inconsistent with the health care ethics framework found in both the Georgetown construct and the global bioethics frameworks. For example, one ethical implication of not recognizing the potential for vulnerability is receiving biased, and judgmental responses, or care that is not culturally competent or knowledgeable about FGC.

The bioethical frameworks demand a moral obligation to behave in a manner that benefits the patient and ethically performs the work of care. To not do so is what Tronto refers to as a “moral failing.”¹⁹⁶ According to the Barcelona Declaration, care is central to the expression of vulnerability. In other words, “vulnerability is the object of a moral principle requiring care for the vulnerable.”¹⁹⁷ Vulnerability and care cannot be separated. Therefore, as it relates to care, vulnerability requires a response to act. The attentiveness required assists the health professional to be keenly aware of potential human rights dangers in the context of care. There is a sense of responsibility to do so, especially as it relates to protecting those who are deemed vulnerable in health care situations. Robert E. Goodin argues that we bear special responsibility for protecting those who are vulnerable.¹⁹⁸ However, Tronto cautions that care does not mean that the carer assumes that they can define the needs of the vulnerable.¹⁹⁹ This seemingly paternalistic method of care usurps the autonomy of the patient. At times the dangers that are faced by the patient are at the hand of the carer, protection for women who choose FGC surgeries. The protection

necessary is one that safeguards against their autonomy or dignity being threatened.²⁰⁰ This shows the influence that human vulnerability has on constructing a model of care for not only women who choose FGC surgery, but also for those experiencing all of the consequences of the surgery.

One of the influences of the principle of human vulnerability is that it elicits action on behalf of the vulnerable. Women undergoing FGC require attentiveness and responses that do not impede the benefits afforded to those who are in our care. For patients to not benefit from care is counterproductive to the goals of medicine, and renders care that is ineffective and insufficient. The principle of vulnerability gives rise to a level of attentiveness that may not otherwise be present, i.e., to protect those who are in our care. Explained earlier in this chapter, care is by its very nature responding to situations and circumstances of vulnerability.²⁰¹

There is undeniable ethical significance of the principle of vulnerability and care. The significance lies in the moral responsibility to attend to the needs of particular other for whom we take responsibility.²⁰² According to Virginia Held, in order for persons to thrive, their flourishing hinges on the care that those who need care receive. Human flourishing can be associated with quality of life, especially for women who choose FGC. Since quality of life is based on the ethics of personal autonomy, which means people make decisions and express their own judgment concerning the quality of their own lives,²⁰³ protecting the vulnerable, namely women experience FGC is being attentive and responsive to possibilities of actions that threaten the dignity and autonomy of the patient.

V. Conclusion

The concept of respect for human vulnerability is regarded as a significant principle in discerning an adequate model of care for refugee women who will choose to undergo FGC. The

significance of the principle of respect for vulnerability lie in the *Universal Declaration of Bioethics and Human Rights* assigns first place to the principle of respect for human dignity, human rights, and fundamental freedoms.²⁰⁴ In other words, all of bioethics, including notions of care, begins with respect for human vulnerability. Considering the concept of the principle of vulnerability allows for the ethically grounded standard to illuminate the inherent dignity and equality of all human persons, especially women who chose to undergo FGC. In doing so, a determination can be made concerning the reality of the vulnerabilities women experiencing FGC in a non- FGC context who are in need of care. One of these realities includes discrimination.

The idea of vulnerability is a daunting subject. It is daunting because the discourse concerning vulnerability suggests that all of humanity is vulnerable to some degree regardless of the context. More specifically, vulnerability refers to those individuals whose autonomy, dignity or integrity are in danger of being ignored, abused, or unrealized. Vulnerability denotes powerlessness, upstages our affair with self-reliance and self-sufficiency, and illuminates our reliance, a reality not easily embraced.

The principle of respect for human vulnerability is a relational concept and is realized in the context of relationship, namely between the patient and the health practitioner. [Article 8] of the UNESCO Universal Declaration on Bioethics and Human Rights make clear that when caring for other, respect for vulnerability and personal integrity must be observed. In addition, the principle of respect for human vulnerability allows for guidance in a situation that might otherwise cause indecision about how to proceed with care. The principle of respect for human vulnerability compels us to respond. In fact, respect for vulnerability makes clear there is an obligation to respond. That is, there is a moral responsibility and obligation to protect.²⁰⁵

Vulnerability as illuminated asks us to take action.

Refugee women experiencing FGC in non-FGC contexts are prone to specific vulnerabilities highlighted earlier in this chapter. They are specific because the particular women observed belong to groups that are often deemed vulnerable- namely women with different ethnicities and socioeconomic levels. Layers of vulnerability emphasize the importance of paying attention for opportunities where the vulnerabilities of the cared for are exasperated rather than put an end. In practice, the response is action. The action realized is in protecting the autonomous decisions that bear witness to the quality of life decision of the patient who chooses to undergo FGC. The principle of respect for vulnerability emphasizes the need for attentiveness and responsiveness for those whom we take responsibility. The ethics of care advances the notion that there is a course of action within the context of the relationship between the health professional and the patient. The outcome of attentiveness and responsiveness is protection. The ethics of care asserts that there is a moral importance to responding to and meeting the need of the other and in discerning what is morally best, namely protection. In light of the principle of respect for human vulnerability, which hinges on human dignity and rights and freedoms, the ethics of care affirms our moral responsibility to protect those who are deemed vulnerable. It also obligates us to protect those who are incapable of taking action that fosters quality of care for the patient, especially for refugee women who choose FGC surgeries.

NOTES

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Chapter 7: A New Model of Care

Care ethics is a theory that receives, at times, controversial attention. This concluding chapter is first an examination of the scholarship on care and a report on the findings. Specifically, this chapter will focus its attention on what the new model of care should be for women who choose to undergo FGC. The chapter will report the outcomes from the analysis of earlier chapters, as the ideas and principles examined are key in constructing a new model of care. The results of the inquiry on care theory will help to construct a new model of care that will make positive steps toward the overall health and care of the patient, since the patients, specifically refugee women who will choose to undergo FGC, are in need of help. Drawing on their mutual focus on relationships that are not equal and dependent; and the attention given to attempting to understand “what morality would recommend, and what is morally best for us to do,”¹ the ethics of care and the theoretical-juridical and expressive-collaborative models have implications for discerning the ethical dilemmas that are present in the health practitioner-patient relationship. The implications are framed and contextualized to develop a model of care.

I. Defining Care

Care theory is a dominant feature in health care. At a very basic level, care is relational. That is, care is first and foremost a relationship between individuals.² On the one hand, there is an individual who needs care and support from another individual, and on the other hand, there is a person who gives care.³ This relationship is called the activity of care.⁴ Although there are a host of different scenarios that make up the context of relationships- for example, family members and friends- for the purposes of this dissertation, when referring to care and the care relationship, the main actors are the patient and the health practitioner, specifically, women who choose to undergo FGC surgery and their health care practitioners. When speaking about the

relationship of care, Ruud ter Meulen explains, people offer help and care because they can identify with what it is like to be in the position of needing support.⁵ They are concerned about the needs of those who are sick and those who are in need.

The findings from the analysis on care show that when the word care is used, it is understood that the expression describes the interrelatedness and the “daily affirmations of connection.”⁶ For example, many individuals use the language, to take good care. Virginia Held explains that the phrase is used to mean a multiplicity of things, however when expressed with feeling, as sometimes it is not, it means to stay out of harm's way, or “I care what happens to you so take care of yourself.”⁷ Care is expressed as a term of affection, used when someone has been sick or when persons are bereaved. Others use care to express a need to be watchful or prudent. Held argues that the expression is very different than the work and tasks of care. Taking care of a person for whom there is responsibility, who is dependent or needs care, is a fundamental component of care.

The practice of care is an activity. The distinction is between care as the activity of taking care of someone and the mere “caring about” of how we feel about certain issues.⁸ While there are many nuances and difficulties with the distinctions of care, many scholars agree that what is relevant to the ethics of care is the activity involved for caring for those for whom we have responsibility. The practice of care extends beyond “warm fuzzies” and lip service to the energy and engagement between persons.⁹ Joan Tronto and Bernice Fisher describe care as a variety of activities that include “everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible.”¹⁰ Tronto further explains that the world referred to in her description of care goes beyond the relationship of care between two people. The world, notes Tronto, “includes our bodies, ourselves and our environment, all of which we seek to interweave

in a complex and life sustaining web.”¹¹ It is in Tronto’s illustration of care that care is holistic. That is, care involves every dimension of life. It is through the existence of individuals in the world that people live and seek to thrive.

Another finding garnered in the exploration of care is that it manifests itself differently according to the diversity of individuals and groups. Therefore, in defining care, an important feature is meeting the needs of individuals in relation to their particular circumstances and wishes.¹² This also suggests that care must make room for diversity of cultures. In other words, the care relationship must allow for a diversity of values, customs, and beliefs that impact the care relationship. Care then includes meeting the need of the patient based on the situation that brings her to the care relationship, which is comprised of understanding the contextual features of the person in need. An illustration of this situation can be found in women who choose FGC surgeries in a non- FGC context.

The contextual features concern both the context in which women currently live and the cultural context in which they see themselves in the world. Care, then, is fostered through relationships. Care in the normative framework of the ethics of care is a relational activity. It attends to relations between the person who is engaged in the task of caring and the person being cared for. If care ignores the relational component of care, it remains reduced to the dominate culture framework of individual interests, abstract meaning of salient moral issues, and unbiased and rules- based approaches. Care quickly becomes performance based instead of relational and concern for the well-being of other. For example, care that ignores relations leaves open the door for abuse seen so often in elder care centers and other care systems where individuals are dependent. Meeting the needs of the person for whom we take responsibility is an essential component of care.

However, if care is left only to the act of meeting needs and void of intention and attitude then one could say that it is morally suitable for health care worker to intimidate vulnerable patients who depend on the caregiver who displays disinterested, cruel, and unkind attitudes. The character and kindness of the health care worker is related to the care that is extended. All care, described Held involves attentiveness, sensitivity, and responding to needs. There is a diversity of needs that range from basic, for instance drinking water to stay alive, to more delicate needs for example those needs that include emotional, psychological, and cultural needs.¹³ As the findings have indicated from the examination on culture, values, beliefs, practices, and customs are features that make up culture. When women choose FGC surgery, they do so based on the practices and beliefs of their culture and bring these values to the health care relationship. The exclusion of the values of care lends itself to the dreadful practice of abuse, oppression, and discrimination as realized in the case of women, minorities, and those individuals who are often marginalized and mistreated. The cultivation of the practice of care concerns itself with what Held illustrated as the effectiveness and efforts to meet needs, but to also be aware of the motives by the carer in which care is provided.¹⁴ The practice of care seeks good relations.

Care is expressed in various ways. Since care is a relational endeavor, it manifests itself in four different ways. These four types of relationships of care are, ‘caring about,’ ‘taking care ‘of,’ ‘giving care,’ and ‘care receiving.’ According to Tronto, too, ‘caring about’ others requires recognition that care is necessary.¹⁵ Recognition is a theme mentioned in Chapter 5 of this dissertation. Recognition is not only identification it also has to do with respecting and accepting differences, an idea reported on later in this chapter which is critical to working with women who choose FGC surgery. Caring about, involves an evaluation that the need of the individual

should be met.¹⁶ Important to the care of refugee women who choose FGC surgery is that ‘caring about’ is culturally influenced and is realized according to the individual.¹⁷ That is, some people will care about an issue, for example giving to the poor on the street, and others will not. However, in the health care setting, what is important to observe is that the need of individuals who require support must be met. A second type of connection realized in the relationship of care is, ‘taking care of.’¹⁸ The process that entails ‘taking care of’ has to do with taking responsibility for the recognized need and discerning how to respond.¹⁹ Critical to the idea of ‘taking care of,’ is engagement. ‘Taking care of’ is engaging in the action required to attend to the unmet need. Important to the care of refugee women who choose FGC surgeries in non-FGC contexts, ‘taking care of’ embodies the “notions of agency and responsibility in the caring process.”²⁰ Regarding the idea of agency, to assert agency, one needs to exercise rational choice.²¹ According to Susan Sherwin, “women who choose some of the controversial practices, i.e., abortion and cosmetic surgery are exerting agency, clearly they are making choices and often those choices are rational under the circumstances.”²² For women who choose FGC surgeries, they meet the demands of autonomy and are making rational choices.

A third phase in the process of care offered by Tronto is care giving. Care giving, a process most related to health care ethics, means unequivocally meeting the specific needs of particular other and care. Care giving requires that the health practitioner and patient make contact. The fourth and final phase of the process of care is care receiving. Care receiving, explains Tronto, is the phase in care where the patient will respond to the care received.²³ A response from the patient is the only indication that the need has been met.²⁴ Care-receiving is critical in the relationship between the health practitioner and the patient, namely women who choose FGC surgeries and are in need of care, because the concept will also assist in signaling whether the

autonomous choice of the woman choosing was honored and if the patient's quality of life has been improved by receiving care. What is important in defining care, using some of the offerings of Tronto, is that each element in the process of care is connected, fostering a more balanced interconnection of care, especially as it concerns the health professional providing care for women experiencing FGC. Care will lead to some type of action.²⁵ Defining care gives place to what care is. However in constructing a model of care for women who choose FGC and are in need of help, the characteristics of care determine what care should be.

A. Characteristics and Constructing Care

In an effort to establish a new model of care, this section will report the findings of the review and study the scholarship on care. The characteristics of care discussed here have implications for developing a model of care. Establishing a framework of care allows for implementation of characteristics and features of care that are either currently underrepresented or not represented at all. An example of a feature of care that is currently underrepresented is respect for cultural diversity and cultural competency²⁶ as it relates to working with groups of people who have different cultural traditions, values, and beliefs. How care is applied, and, more specifically, how care is ministered to refugee women who will choose to undergo FGC is dependent upon the sensitivity to culture and the competency, i.e., cultural competency, of the health care practitioner.²⁷

In the inquiry into care, one of the findings is that there are four moral qualities of care.²⁸ They include, attentiveness, competency, responsibility and responsiveness.²⁹ These features of care are interconnected. For instance, Ruud ter Meulen explains that responsiveness takes for granted that there is attentiveness, and responsibility takes into consideration that there is competency.³⁰ The four characteristics are components of one whole, which is the activity of

care.³¹ Attentiveness refers to recognizing that there is a need that requires care as explained earlier. It also denotes that the carer is paying close attention to the needs of the patient and attending to the patient's wishes. In applying attentiveness to the care relationship, it is incumbent on the health professional to respect the rights of the patient to choose by honoring the wishes of the patient rather than becoming a barrier. If attentiveness is not applied, then the needs of women choosing FGC cannot be recognized.³² In considering the characteristic of care and constructing a model of care for women experiencing FGC, the findings from the investigation on respect for human vulnerability are useful. For example, in investigating respect for vulnerability, one finding reports that the health care professional must be attentive to the opportunities for vulnerability to take place. That is, paying attention to occasions for autonomy of the individual seeking care to be threatened and ignored.³³ To not do so in the activity of care is what Tronto refers to as a "moral failing."³⁴ Attention forms the basis of relationship, and since care is first and foremost a relationship between the patient and the health practitioner, it must be part of the model of care for refugee women who choose FGC surgeries.³⁵

The concept of responsibility is another characteristic realized in the activity of care. The examination of responsibility, as explained by Daniel Engster, "is the moral obligation to meet others' claims for caring thus rests upon the intuitive idea that human life and basic well being are valuable and should be supported."³⁶

In addition, according to Tronto, the process of care that refers to 'taking care of', places responsibility into a category that has to do with what is right and wrong.³⁷ That is, when we take on the concern for care, we do so because we can participate in meeting the needs for care, and so we must.³⁸ Virginia Held describes that there is a compelling moral un-deniability of attending to and meeting the needs of those for whom we take responsibility.³⁹ That is, one

cannot deny the necessity of responding to the needs of those who are in our care. One example gleaned from the examination on the responsibility is the duty of the health care professionals to protect those who are vulnerable and are in vulnerable situations. It is the responsiveness of the health practitioner that allows her or him to engage in both meeting the needs of women who are experiencing FGC and to protect those who are vulnerable. Engagement also indicates that there is conversation to determine the care needed. It is here that respect assists to facilitate a positive outcome in the activity of care. The lack of responsiveness can make the activity of care ineffective.

B. Goals of Care

This section will discuss the outcomes from an examination on the aims of care described in the scholarship on care. The outcome of the investigation revealed common themes and threads that help to shape and focus care. The examination of the goals of care will, in addition, help illuminate what might be the outcome for the health care professional involved in meeting the need of care. Garnering what reflects the goals of care has been a central theme in this dissertation. Its centrality lies in constructing a model of care for refugee women who choose FGC surgeries. As it relates to health care ethics, the goals of care are facilitated through the Georgetown framework of ethical principles. However, in discerning what the care should be for women who choose FGC the global bioethics construct is particularly relevant as demonstrated through this dissertation. An example of how global bioethics is specific to refugee women who choose FGC surgeries is the respect for cultural diversity investigated in chapter 5 and recounted further later in this chapter. Respect for cultural diversity allows for a more expansive point of view, a perspective necessary in caring for women who experience FGC.

Caring for other is the task of health care. The fundamental aim of healthcare is further articulated as the improvement of quality of life for all those who need and seek care.⁴⁰ While quality of life has not been fully explored in this dissertation, it has been illuminated throughout, as it is a goal of care. An important outcome of the findings in the exploration of care and the goals of care is through the connection of autonomy and quality of life, especially for women who choose FGC surgery. For example, one way to consider the connection of care and respect for autonomy is through the features of patient preferences (autonomy) and how patient preference contributes to applying respect for autonomy to care. Patient preferences are “ethically significant and what is essential to care.”⁴¹ Since patient preferences can also be articulated as autonomous choice, the preferences of the patient become the ethical “nucleus”⁴² of the relationship between the health professional and individual receiving care.

There is an unmistakable ethical significance to patient preference, i.e. autonomy that is critical to care, but especially to care for the group of women represented in this dissertation. Patient preferences are ethically significant because they manifest the value of personal autonomy that is deeply rooted in our culture. This is particularly true and challenging for women who are refugees and choose to undergo FGC, and for the future generations of women who will also choose to employ their beliefs and values associated with the cultural custom. Another way of articulating the goal of care is assisting individuals to achieve at least a basic level of well being.⁴³

Another finding of the outcome on the analysis of the goal of care is how both the principles of beneficence and non-maleficence significantly contribute to the improvement of quality the of life and well-being, i.e., the goals of care. Within the framework of health care ethics, the principles of beneficence and non-maleficence describe the moral obligation to act for

the good and well being of others,⁴⁴ namely refugee women from FGC contexts who live in non-FGC contexts and make the choice to undergo FGC surgeries.

The primary goal of non-maleficence, which is under rigorous examination in Chapter 4 of this dissertation, is to “do no harm.” On the other hand, the principle of non-maleficence designates a moral obligation to refrain from inflicting harm. As it relates to healthcare ethics, the health care practitioner has an obligation and duty not to harm those who are in her/his care. In the larger framework of health care ethics, non-maleficence plays a critical role in patient care. For example, according to Jonsen, Siegler, and Winslade, the principle of non-maleficence is linked to the quality of life maxim, and it is the patient who determines what is harmful and what is not.⁴⁵ The patient, in addition, decides what is quality of life.

The patient’s perspective on what indicates harm to her is critical to determining a model of care for refugee women experiencing FGC.⁴⁶ Her perspective and outlook concerning her care is what Jonsen, Siegler and Winslade refer to as patient preferences.⁴⁷ The significance of the preferences of the patient rests in the fact that patient preferences are “essential to good clinical care”⁴⁸ specifically, care for refugee women who choose FGC surgeries. In the in-depth examination of the principle of non-maleficence, it draws attention away from the health practitioner and focuses on the patient. This not to say that the principle does not hold medical professionals to a standard, in fact it obligates them. However, in the complete examination of the principles of non-maleficence and beneficence, the outcome suggests that the patient determines her course of care. The obligation of the health practitioner is to minister care in a way that supports the patient’s desires regarding the course of care.

C. Obligation of Care

In determining and developing a new model of care for refugee women who choose to

undergo FGC, the concept of obligation is critical. Its importance lies in the question raised in this dissertation; does the obligation of care imply that the physician or health care professional has a duty and responsibility to honor specific health care needs for the female patient in a culture that is in opposition to the practice? While there may be opposition to the practice of FGC it is important to note that FGC is not illegal in the U.S for those women who are eighteen years of age and older. The opposition of the medical intervention is described as disagreement or lack of professional knowledge and training about the surgery. In a study and examination on the notion of obligation, the findings point to the UNESCO *Universal Declaration on Bioethics and Human Rights*, and the Georgetown health care ethics frameworks which positively determine the duty and responsibility of the health care practitioner to honor the specific health care needs of the patient, namely refugee women who choose FGC surgery. Care, and specifically health care is facilitated through these frameworks.

The result of the inquiry into the concept of obligation demonstrates that duty is intimately and specifically connected to the principle of non-maleficence and beneficence. The concept of obligation promotes an optimistic, less oppositional view and assists in answering the query of this dissertation concerning how health care professionals should respond to the care of women whose intention is to undergo FGC surgery. As the outcomes garnered from the investigation of the notion of obligation, the idea is, in addition, linked to respect for human vulnerability and respect for cultural diversity, examined in this dissertation as two features that must be included in the constructing a new model of care for women experiencing FGC. Both respect for human vulnerability and cultural diversity are specific to global bioethics framework, which has its underpinnings in human rights.⁴⁹ Reported in the section above, the principles of beneficence and non-maleficence are clear about the obligation to care.

The conclusion of exploration into the principle of beneficence finds that the acting on behalf of others, specifically women who choose FGC surgery, is the essence of the principle of beneficence. In fact, the findings obtained in the scholarship on the principle of beneficence, refers to the principle as “the moral obligation to act for the benefit of others.”⁵⁰ In other words there is an obligation to facilitate care, i.e., health care for the benefit of those in need. The significance and the implication of the principle of beneficence is that the principle gives guidance and action about how the concept is applied to refugee women who choose to undergo the FGC surgery. In addition to the significance of beneficence and how it is applied to women experiencing FGC, beneficence gives necessary guidance for the care of women who choose to undergo FGC. As mentioned in chapter 4 , one of the dilemmas raised by FGC in the U.S. is that the custom is quite foreign to the U.S. health care system. A further finding in the outcome of the examination on obligation is that one of the primary characteristics of the care of women experiencing FGC is the responsiveness of the health practitioner.⁵¹ That is, for the health care practitioner to act on behalf of the other. To attend to the welfare of others represents and exemplifies the goal of medicine.⁵² Acting in the interest of and for the benefit of others is intimately tied to the objective of medicine. Explained earlier, health professionals are obligated to act in a manner that ensures positive outcomes and does not undermine the patient’s autonomous choice. The results of the examination of Frankena’s framework of beneficence finds that there is support for acting on behalf of others, particularly refugee women who choose FGC surgeries. Frankena’s framework also provides the guidance of health professionals and illustrates that the primary concern of care is beneficence rather than non-maleficence. To discern that the aim is to act on behalf of those who are in need of care affirms that Frankena’s framework is needed in the model of care for women who choose FGC surgery. Concerning

obligation, “Obligations of general beneficence rest on the mere fact that there are other beings in the world whose condition we can make better.”⁵³

A further result in consideration of the principle of non-maleficence is observed through the lens of remediation. Remediation fosters prevention of the alleged harmful consequences associated with FGC surgeries, namely certain types of cutting that are reported to be the most severe of the surgeries and present the most long-term health complications.⁵⁴ Being able to lessen the harm by using less invasive interventions assists in framing a response to the ethical tension between the health professional who is concerned with non-maleficence (do no harm) and the patient whose life intention is to undergo FGC surgery. A major conclusion drawn from the examination on obligation via non- maleficence and beneficence is that lessening the harm contributes to the outcome of the obligation of care. In actual practice, FGC surgeries are safer under the guide of medically trained professionals rather than unskilled and unprepared hands.⁵⁵ Non-maleficence, then in this way, supports a construct of what the care is for women who choose FGC.

The investigation of non-maleficence and beneficence afforded further findings crucial to the construct of care for women experiencing FGC surgeries. Related to the obligation of care and a positive outcome for the patient is the idea of harm reduction. Harm reduction is minimizing the health consequences associated with FGC surgeries. Harm reduction, as it concerns women who choose FGC surgeries, is a feature of non-maleficence and is essential to the obligation of care. If the surgery can be done in a way that reduces harm, it has implications both for healthcare professionals and for women who voluntarily choose to undergo FGC. One outcome of the exploration on harm reduction is that it facilitates guidance for health care practitioners who encounter women who intend to pursue FGC. The surgery can be done in a

way that prevents harm incurred by unsanitary and non-medical environments that can cause damage to patients. Related to the harm reduction and positive outcomes for the patient, the examination affords a significant finding for the model of care. That is, it is critical to approach FGC as the medical procedure that it is, therefore ethically bound to all of the standards, processes, values, and norms that other medical procedures adhere too. It is not only cultural tradition it is a medical intervention.

With regard to obligation, further findings of the study find that respect for human vulnerability concludes that there is a moral obligation to care. This type of care is in the context of protection. [Article 8]: Respect for Human Vulnerability and Personal Integrity which is included in the construct of the UNESCO *Universal Declaration on Bioethics and Human Rights*, describes that the “principle of ‘respect for human vulnerability and personal integrity’ should be observed and also makes clear the obligation of care.”⁵⁶ The Declaration explains that vulnerability is the object of a moral principle, which necessitates care for those who are in need,⁵⁷ particularly women who choose FGC surgery. Findings report that the Barcelona Declaration expresses that “the vulnerable are those whose autonomy, dignity, or integrity is capable of being threatened.”⁵⁸ The implications here are women who choose FGC surgeries in a non-FGC context will need care in the form of protecting autonomous choice, an important feature in a construct for the new model of care.

Since health care ethics is related to the rights and privileges of all human beings, which include, for example, the right to life, and the right to choose, then respect for human dignity is paramount.⁵⁹ In reporting the further findings, garnered respect for human vulnerability cannot be separated from human dignity.⁶⁰ Vulnerability requires care. Vulnerability is the intention, if you will, of rendering particular individuals and groups of people vulnerable,⁶¹ namely refugee

women who choose FGC surgery. The designation of the principle of vulnerability makes clear that there is a moral obligation to act. The results of the examination of vulnerability, denotes that there is an opportunity for the human rights, dignity, and integrity of women who choose FGC to be thwarted.⁶² The Barcelona Declaration notes care is central to the expression of vulnerability. In other words, “vulnerability is the object of a moral principle requiring care for the vulnerable.”⁶³ Applying vulnerability to women who choose FGC surgeries, vulnerability denotes an obligation on the part of the health care professional to provide care and must be included in the as a feature in the construct of care for women who choose FGC surgeries. In fact, it is the obligation of the health care practitioner to do so.

II. Models to Care

A. Ethics of Care

The ethics of care is the feminist approach to mainstream bioethics. The scholarship in the ethics of care illuminates diverse meanings and interpretations of the ethics of care, but consistently focuses on caring relationships, an implication for care. Included in the interpretation of the caring relations between people are the experiences of particular others, their individual insights, points of view, and emotions.

The ethics of care is also a moral theory grounded in the context of bioethics. Because bioethics and global bioethics alike “draw deeply from a moral and great religious ethical traditions.”⁶⁴ The results from the inquiry of the theory reveal that it is applicable to women who are experiencing FGC and are in need for care. One reason for the ethics of care's appropriateness is that according to Ruud ter Meulen, care is in the first place a relationship between individuals⁶⁵.” The ethics of care focuses on caring relationships. That is, “there is a compelling moral salience to responding to the need of particular other for whom we take responsibility.”⁶⁶ The ethics of

care values relations of care and embraces the mutual dependence that connects people. It places importance on the experiences of others individual insights, their points of view, and their interests. As it relates to the practices and understanding of others, the ethics of care lends itself to the need to have a more balanced perspective of others, namely refugee women who choose FGC surgery. Concerning the provision of care for patients from other cultures, these perspectives are called the emic and etic perspective investigated in chapter 5 and reported more fully later in the section on attentiveness to cultural features.

The findings of the outcome on the analysis of the ethics of care, is that Virginia Held offered several features as a moral theory. One of the features of the ethics of care and perhaps one of the most important findings in the study of this theory is the conception of person.⁶⁷ The ethics of care pay close attention to cultivating relationships and meeting the needs of particular other,⁶⁸ relevant to care for women who choose to undergo FGC surgery. The theory demonstrates the centrality of the carer as a caring person. The ethics of care begins not with the focus on self-sufficient or self reliant individuals endowed with the faculty of reason, rather it begins with persons as “moral subjects capable of actions and of shaping lives and institutions and societies over time through cultivating in themselves and others certain characteristics and practices and values.”⁶⁹ These characteristics, practices and values begin with self-awareness and are inclusive of moral responsibility and are interconnected with the social context in which a person is reared.⁷⁰ It is in the interconnectedness of the social context that the ethics of care finds it relevance in constructing a model of care for women who choose FGC surgery. Related to cultural diversity, the context in which a person is reared, namely women who are experiencing FGC, influences health decisions and the quality of life of the patient. This is also true for the health professional whose cultural context may be otherwise different from the

patient. The person in the ethics of care is a relational person with specific social relations to family and the wider context of other social groups and communities. These social relations are critical to persons as moral agents since context has influence and meaning for how a person responds to their moral responsibility, particularly the health care practitioner.

Another feature found in the outcome of the investigation on the ethics of care includes the emphasis on the value of emotion. In the analysis, Held notes, however, “not all emotion is valued, but in contrast to the dominant rationalist approaches, such emotions as sympathy, empathy, sensitivity, and responsiveness”⁷¹ are encouraged and critical to the process of moral decision-making and knowing what is the right thing to do, particularly in relational and personal contexts. The connection, or link if you will of the emotional characteristic of care is that both sensitivity and responsiveness are themes explored throughout this dissertation, particularly as it concerns constructing a model of care for women experiencing FGC. Sensitivity is particularly important as it is linked to cultural sensitivity examined in Chapter 5 and a critical feature of a new model of care. These emotions noted by Held in the context of relations, moral responsibility, and care, are active and not static. Arriving at what morality advocates, or would recommend includes not only reasonableness and logic, it includes emotional responses and imagination. Imagination here is not used in a fanciful way but in a way that garners resourcefulness in discerning morality.

A final feature found in the investigation on ethics of care framework offered by Held is that it “rejects the view of the dominant moral theories that the more abstract the reasoning about a moral problem the better because the more likely to avoid bias and arbitrariness, the more nearly to achieve impartiality.”⁷² The ethics of care respects the moral claim that the particular other has with whom the relationship is shared. The dominant moral theory however, neglects actual

relations and disallows relationships to take priority over the requirements of partiality.⁷³ Yet the ethics of care sees that the moral claim of other trumps the generalized moral rule against bias. It recognizes the prominence of the moral claim of particular other to the shared relations and understands that it is more important than universal rules of impartiality.

The conclusion of the results on the ethics of care is that it provides a sense of balance to what tends to be unbalanced in traditional moral theories. Traditional moral theories have a propensity for rules, rights, abstract reasoning and an individualist orientation. The ethics of care, on the other hand, considers what is missing and what is obscure. It attends to persons in relations of care, the self as the moral agent, community, and the nuances of contextual considerations.⁷⁴ It is the influence of what is missing in other moral theories that makes the ethics of care a paradigmatic theory applicable in working with sociocultural contexts, that is contexts in which women who choose FGC.

B. The Theoretical-judicial and Expressive-collaborative Models

The theoretical-judicial model and the expressive-collaborative models are two models that provide a conception of morality and a view about the nature and the point of morality.⁷⁵ They are not moral theories. The theoretical-judicial model defines morality as rules and guidelines that determine what should be done. Margaret Urban Walker describes the theoretical-judicial model as an “internal guidance system of an agent that could be modeled after some kind of theory and represented by a cluster of beliefs.”⁷⁶ On the other hand, Urban Walker offers an alternative view for moral inquiry, namely the expressive-collaborative model. The expressive collaborative model does not depend upon a set of rules or guidelines for moral inquiry, rather it relies on a “continuing negotiation among people”⁷⁷ to reach moral understandings. The negotiation between people allows for the experiences of individuals from different contexts,

namely women who from FGC environments to define their moral lives,⁷⁸ and includes respect in meeting the needs of others.

The outcome of the examination on the theoretical-juridical and expressive-collaborative models of care, find that that the models has implications for what care should be for refugee women who choose FGC surgery. The models offer a framework that describes what care looks like in practical setting. The theoretical-juridical model offers a moral guide that defines what is included when we care for others. Its counterpart, the expressive-collaborative model emphasizes the critical nature of attentiveness, and responsiveness. Given the investigation into both attentiveness and responsiveness and their fundamental nature in the care relationship, both models are conducive. An important finding in exploring this model is it also includes the concept of respect in an effort to apply attentiveness and responsiveness in specific situations with particular persons, namely women who choose FGC surgeries and are in need of care. The activity of care is more than achieving certain goals. Care includes doing so in a manner that is attentive, responsive, and respectful.⁷⁹ Caring characterizes a mixture of the theoretical juridical and expressive-collaborative models of care.⁸⁰

The theoretical-juridical model, for example, regards morality in terms of rules and guidelines that determine what should be done. Using the Georgetown and Global Bioethics frameworks investigated in this dissertation to discern what care should be for women experiencing FGC surgery are guidelines for how care should be done. The frameworks, for example, include, respect or autonomy and human vulnerability, respect for cultural diversity, and the principles of beneficence and non-maleficence. The outcome of the query into the expressive-collaborative part of the model reveals that this arm depends on an open and ongoing dialogue among individuals to reach moral understandings⁸¹ that are fundamental to the activity

of care. To reach an understanding of what the patient desires is critical to the relationship between health care practitioner and patient. It is in the framework of the expressive-collaborative model that allows for the care of patients, that is, women experiencing FGC, to have a positive outcome. Upon further analysis of the expressive-collaborative arm of the model, the results indicate that the paradigm emphasizes the significance attentiveness, responsiveness, and respect, in the reality of care relationship. The care relationship is predicated on meeting the needs of particular other (who are in specific circumstances) who seek help.⁸² As mentioned earlier, the probe and consideration of attentiveness, responsiveness, and respect are central to the model of care for women who choose FGC surgeries. Responsiveness is highlighted to make the connection to cultural sensitivity and care, which is a construct needed in determining what care should be for refugee women who choose to undergo FGC.

The results of the investigation into responsiveness show that it is related to communication with a mutual understanding of the patient whose cultural context is different from that of the health professional. It is here where the expressive-collaborative is relevant and assists with the practice of responsiveness need in the model of care that meets the needs of women who choose FGC surgery. Joan Tronto explained that responsiveness is not putting ourselves in the position of others rather it is considering the others' position from the place where it is expressed,⁸³ namely from the position and the cultural context of women who choose to undergo FGC surgery and are in need of care. In this way, the health professional is involved from the perspective of the patient and not from the assumption that the patient's viewpoint is the same.⁸⁴

The interrogation of the concept of attentiveness garners significant findings. The most meaningful outcome of the query is that attentiveness is necessary if care is to be realized.

According to Tronto, attentiveness is one of the ethical elements of care.⁸⁵ It was further found that some scholars conclude that attentiveness presupposes responsiveness.⁸⁶ It is important to mention this finding because, in caring for the vulnerable, a concept fully examined in chapter 6 particularly applicable to women who undergo FGC surgery, attentiveness and awareness are key to the contextual features that produce situations where women experiencing FGC are vulnerable. That is, conditions where their autonomy or dignity are in danger of being jeopardized or discriminated against because of their ethnicity. Attentiveness allows for the health practitioner to be concerned with the needs of the patient. According to Tronto, if the health care professional is not attentive, ignoring the needs of the patient, then the practice is one of an unethical nature.⁸⁷ The bioethical frameworks demand a moral obligation to behave in a manner that benefits the patient and ethically performs the work of care. To not do so is what Tronto refers to as a “moral failing.”⁸⁸

Since the focus of this dissertation is on a specific group of women in a distinct situation, with the aim of seeking and finding care, the results of the examination of the features of the theoretical-judicial and expressive-collaborative model are reasonable and justifiable in the establishment of a new model of care. The models not only make room for the inclusion of the Georgetown and Global bioethics frameworks that are fundamental to cause of providing ethical care, the models offer practical application for a model of care for women who choose FGC surgeries, especially in contexts where FGC surgery is not normative. The theoretical-judicial and expressive-collaborative models, and particularly the expressive-collaborative arm permit the inclusion of expanded features and components for a new model of care that supports women who choose FGC surgery.

III. Expanded features and components for a new model of care

A. Attentiveness to Cultural Features

Many of the approaches and models of care avoid the inclusion of cultural sensitivities, and competencies. These features are critical if there is going to be adequate health care provision for women refugees who have experienced FGC and for those women who will choose to undergo FGC. The findings from the examination on cultural sensitivity and cultural competency have lead to how to include attentiveness to cultural features as a component in a new model of care. An example of the attentiveness to the cultural features of women from FGC cultures is paying attention to the strong value of community over individuality which must be honored if there is going to be sufficient and attentive care for this group of women.⁸⁹ There is a changing demographic in America and the shift requires “that all practitioners and students of all health professions develop cultural competence, communication.”⁹⁰

In the previous section, the results of the investigation on attentiveness were explained. The findings illustrate that attentiveness carries significant weight. Care cannot be fulfilled if it doesn't include the essential feature of attentiveness. To validate the place of attentiveness in the activity of care, particularly for women who choose FGC surgery Tronto describes attentiveness as one of the ethical elements of care.⁹¹ Further, if the health professional is going to be responsive they must first be attentive.⁹² The attentiveness includes paying attention to the cultural features of the patient, for example, the diversity of values and beliefs brought by the patient. In health care ethics, respect for cultural diversity is associated with the care of the patient. Respect for cultural diversity is also one of the features of global bioethics. Within the framework of the patient-health practitioner relationship, both the health practitioner and the patient bring to the relationship duties and responsibilities to the larger world in which their

relationship takes place.⁹³ In the context of care, the outcomes associated with the survey on respect for cultural diversity inform that culture will influence the preferences of the patient, especially women whose life intention is to undergo FGC surgery. These aspects of culture include lifestyle, values, beliefs, and traditions. The findings of the probe into contextual features unearthed that the health care choices made by the autonomous individuals are influenced by contextual considerations.⁹⁴ For instance, one contextual feature in which health care professionals must consider is the varying influence of community and family, which inspires life decisions and health care decisions, in particular. As it relates to the scholarship, in the case of FGC, the health practitioner observes the contextual features of the patient in conflict not only with his/her culture, but also the practitioner's commitment to the patient.⁹⁵ The scholarship describes that some health practitioners disagree that contextual features, i.e., cultural considerations of the patient are important in determining ethical decisions about care, namely to consider the care of women experiencing FGC. However, scholars argue that the beliefs and practices of the patient's cultural orientation that are culturally different than the health practitioner's is "real and in varying degrees obligatory"⁹⁶ for the patient. Therefore, it is incumbent upon the health practitioner to respect the cultural diversity of the patient and to consider cultural diversity in determining care for women experiencing FGC. Health practitioners have a moral obligation to do so.⁹⁷ Women who have chosen to undergo FGC surgery do so based on their experiences, ideals, values, and their beliefs. Respect for cultural diversity that includes an understanding of the beliefs and ideals of the patient and how they guide thinking, actions, decisions,⁹⁸ are vital and necessary for good patient care. Not only are these cultural characteristics integral to care, they frame how individuals view health and the need for care.⁹⁹

B. Attentiveness, Cultural Competency and Respect

A common theme in the scholarship on care theory is the responsibility for the other, attentiveness, and responsiveness.¹⁰⁰ These elements of care have an explicit characteristic that the person receiving care is part of the caring relationship and must be included. Conversely, in the examination of the literature there is an implicit quality as it relates to the idea of inclusion and particular attention to cultural features. Attentiveness to cultural aspects, cultural sensitivities, and the application of cultural competency should not be implied; rather, these notions must be straightforwardly and candidly expressed and implemented. One of the findings from the investigation on cultural competency is a framework that can be implemented. These outcomes are discussed later in the section on attentiveness to cultural features. It is important to note that the research also found that responsiveness and attentiveness are aspects of any framework of cultural competency. What is critical here is that one of the findings garnered from the exploration of cultural diversity and care, responsiveness, and attentiveness are fundamental to care and a model of care for women who choose FGC surgery must include these elements. When refugee women come to the United States, now a multiethnic society, they bring their health care needs. Sensitivity to values, beliefs, and behavior and applying understanding can improve “communication and care.”¹⁰¹

Reported earlier, the health care profession must not only be attentive, but also must be aware and pay close attention to the cultural features of the patient. One reason as found in the outcome of the study on vulnerability is that some groups of people who are in the racial minority are often exposed to discriminatory behavior.¹⁰² The attentiveness ministered, however, is not only for the patient but also for health care providers who must be aware of their propensity for the lack of cultural know-how.

Attentiveness refers to recognizing that there is a need that requires care as explained earlier. It also denotes that the carer is paying close attention to the needs of the patient and attending to the wishes of patient. When applying attentiveness, it is incumbent on the health professional to afford the patient the right to choose by honoring the wishes of the patient instead of becoming a barrier. If attentiveness is not applied, then the needs of women choosing FGC cannot be recognized and go unfulfilled.¹⁰³

C. Cultural Competency

This section will discuss the findings of the examination on cultural competency. These findings have implications for a new framework of care that includes respect for cultural diversity and cultural competency. Cultural competency entails understanding the importance of social and cultural influences on patient belief and behaviors.¹⁰⁴ The application of cultural competency assists in taking positive steps to responding to the western system of health care that is unfamiliar with FGC. The unfamiliarity produces biased and negative attitudes that foster prejudiced responses that could be injurious to FGC patients.¹⁰⁵ Such attitudes and a failing to understand the contextual features and societal factors of this group of women could serve as unethical barriers to care. Care includes integrating cultural competency into a new model of care that will serve as a strategy for addressing these barriers examined in Chapter 4 of this dissertation. Cultural competency as a component in a new model of care promotes giving attention to the influence of societal factors and cultural features and how refugee women choosing FGC experience and receive care.

The analysis into both cultural diversity, and cultural competency garnered findings that support the diversity of cultures and the right for individuals to participate in their cultural traditions and practices. This outcome is supported by the Universal Declaration on Cultural

Diversity which asserts, “the defense of cultural diversity is an ethical imperative, inseparable from respect for human dignity, culture should be regarded as a set of distinctive spiritual, material, intellectual and emotional features of society or a social group and encompasses lifestyles, ways of living together, value systems, traditions and beliefs.”¹⁰⁶ Culture, it is said, is the lens with which individuals see the world, and the lens extends to health and healthcare.¹⁰⁷

These cultural beliefs and practices are brought to the health care relationship, which exists between the patient and the health care professional. Accordingly, the outcome of the investigation finds that cultural traditions and beliefs influence health decisions and particularly the health decisions of women who choose FGC surgery. Scholars maintain there are four factors in which health care providers must be sensitive, religion, ethnicity, race, and class.¹⁰⁸ Understanding the cultural context of the patient who is choosing to undergo FGC surgery improves communication and enhances care.¹⁰⁹ The cultural sensitivity framework and approach assists in advancing the occurrence of cultural connectedness between the health practitioner and the patient who is in need of care.¹¹⁰ However, there must be more than a cultural connectedness and sensitivity.

In the analysis of cultural competency, the conclusion of the investigation garners that since there is diversity of cultures in the US healthcare context, it requires that health professionals, practitioners and students in health professions, have the ability to communicate, understand, and respect the diversity of cultures.¹¹¹ In other words, health practitioners must understand, appreciate, and work with other cultures and belief systems.¹¹² In order to gain the ability to communicate and understand a framework in which to do so is useful. Cultural competency, as the findings support, is a practical framework in health care to deal with cultural barriers in the clinical encounter. Cultural competency entails understanding the importance of

social and cultural influences on the patient's health beliefs and behaviors.

The cultural competency framework considers how characteristics of culture interact at different levels of health care, for example, in the decision making process of the patient. One example to note in the findings on the inquiry into cultural competency and sensitivity is on religious beliefs. Geri-Ann Galanti explains about religious beliefs, spiritual practices, and health care, that while religion is not a subject of conversation in hospitals; the customs, traditions, and beliefs of patients are. These aspects of religion are often sources of conflict, disagreement, and misunderstanding;¹¹³ however, these aspects play a fundamental role in how patients make decisions about care and about quality of life. Since religion is one of the most common themes that typically justify the cultural significance of FGC, health practitioners would do well to gain an understanding of the religious influences.

While the results of the research on cultural competency found that the framework includes organizational and structural cultural competency, it is clinical care that is related to refugee women who choose FGC surgery. The focus is on the clinical care. That is the relationship between the patient and the health practitioner. This is not to say that the organizational and structural cultural competence is not important-it is. The importance is the long-term systemic change that must be realized at the organizational and structural levels as well, an idea that needs further investigation. The "defining landmarks of cultural competency is for health care practitioners to learn how the behavior of various cultures affects decision making,"¹¹⁴ and to understand how these sociocultural features can be a barrier to care. The sociocultural characteristics are critical to the encounter and must be understood and managed if the model of care for women experiencing FGC will have a positive outcome. Importantly, in the examination of the framework of cultural competency, further findings reveal that the construct is linked to

other aspects of care examined earlier in this dissertation. They are responsiveness and attentiveness. If the model of care for women who are experiencing FGC is going to have a positive outcome which includes quality of life for the patient, care must include attentiveness to the cultural features of the cared for and responsiveness which including reasoning in a culturally competent way.

One of the conclusions drawn from the examination of competency is that an ethical feature of care is competence, described earlier in chapter 4. Observing non-maleficence through Frankena's framework, aiming to promote good first, links competence and cultural competency to care in the following way. First, in promoting good and a positive outcome for the patient, which includes preventing harm, this means that the health professional must be competent. The competency, however, goes beyond the skill required in medicine; competency includes cultural competency in the context of clinical care. The health professional is obligated to be educated about FGC in general and FGC surgeries specifically. The result of the investigation into the cultural competency framework yields the application of the construct, which is necessary for the integration of the framework into the model of care. Because the social-cultural factors are critical to the clinical encounter, Betancourt reports that cultural competence curricula, has been developed for providers.¹¹⁵ The aim of the educational interventions is to "equip health care providers with knowledge, tools, and skill to better understand and manage sociocultural issues in the clinical encounter."¹¹⁶ Attention must be paid to communication. It is important to note that the findings of the research also show that cultural competency is often referred to as "cross cultural," or "cultural sensitivity," education and training.¹¹⁷ To include competence as a part of the "moral quality of care"¹¹⁸ is critical. In not doing so, we have failed. The conclusion of the cultural competency investigation makes clear that the concept is indeed a framework by which

to minister care to refugee women who choose FGC surgeries and who are in need of health care.

D. In a Caring Way: respect for a particular other

This section will present the results of examining the concept of respect. In the UNESCO Declaration on Bioethics and Human Rights, ‘respect for’ precedes two concepts: respect for human vulnerability and personal integrity, and respect for cultural diversity and pluralism. In the examination of the UNESCO *Universal Declaration on Bioethics and Human Rights* discussing autonomy it notes, “the autonomy of others is to be respected.”¹¹⁹ In the Georgetown bioethics framework, respect is linked to respect for autonomy investigated in Chapter 4 of this dissertation. The findings illuminated from this examination require that respect in the care relationship is to recognize and accept the right of the every individual to hold views and values, to make choices, and to take action that are based on their values and beliefs.¹²⁰ Therefore, respect involves not only a respectful manner but also a respectful approach and action.¹²¹ Respectful action taken is manifested in a way that appreciates the value and decision making rights of women who choose FGC surgery. Respect allows for the health practitioner to empower women to act in a way that supports self-determination.¹²²

Further findings with regard to respect, include that it is central to the care relationship. In his list of three basic aims of caring as a practice, Engster describes what he calls a third virtue of caring: respect.¹²³ Because of the centrality of respect to the care relationship, an adequate model of care must include respect. In the relationship between the patient and the health professional, respect regards other as equal. Showing equality in the health care relationship, the health care professional can garner trust from the patient therefore providing a passage to fruitful communication, which is needed in the care relationship. Ministering respect promotes non-partiality and intolerance for prejudice, which, according to findings from the analysis on

cultural diversity, is probable. Respectful care can influence positive responses to cultural practices that are significantly different from the dominant cultural practices of the health professional, especially in the US healthcare context.

As respect is concerned in providing care for women who choose FGC, respect then is critical as it supports women who make the autonomous choice to undergo FGC. They understand what they have chosen and are more than capable of expressing their needs. For a health care practitioner to treat women experiencing FGC with disrespect is degrading and borders on the complete disregard of human dignity.¹²⁴ Engster further explains, “one respects others by treating them in ways that do not degrade them in their own eyes or in the eyes of others.”¹²⁵ In the examination on cultural diversity, one of the findings is that disrespect for the diversity of cultures and an unwillingness to take into account the cultural traditions, which include religion, beliefs, and values of the patient can lead to discrimination and prejudice.

The outcome on the investigation on respect finds that the notion of respect is promoted in the UNESCO articles on vulnerability, cultural diversity, and autonomy. As it concerns vulnerability, examined fully in chapter 6, respect is related to human vulnerability. In fact, the outcome of the research found that respect for human vulnerability is an obligation.¹²⁶ That is, we have a responsibility to regard the fragility of every human being as it is the human condition. The outcome of the examination into respect for vulnerability further finds that “we are all essentially vulnerable and in need of care.”¹²⁷ Therefore, care must include respect for particular other.

The outcome of the analysis of cultural diversity completed in Chapter 5, mentioned in the preceding paragraph of this dissertation, also garners results as it relates to respect and care. For example, when dealing with different cultures, without respect for the differences found in the

diversity of cultures, which can facilitate mutual understanding, the cultural significance of FGC is missed and care is not realized. The findings from the examination on respect for human vulnerability afford similar findings related to respect. Concerning care and particularly care for refugee women who choose FGC who are in need of care, action and intervention are not the primary responses: respect and care should be.¹²⁸

IV. Conclusion

This paragraph summarizes the strategies toward an inclusive and collaborative practice of care that will establish a new model of care for refugee women who will choose to undergo FGC. Included is an expanded view of how the topic of FGC and care is treated currently and what must change. Drawing from the models of care and the other features reported from the examination of the components of subsequent chapters, an expanded, more inclusive, and collaborative practice of care is realized.¹²⁹

Traditionally, FGC surgeries have been handled by mainstream media, and the medical profession with an unyielding prejudice, and an unbalanced, and uninformed view. Unfortunately these claims have been made popular without a balanced assessment of the evidence.¹³⁰ FGC surgeries are seen through the perspective of an outsider or the etic point of view, rather than an emic one. These points of view have left the discourse as one without respect for differences, therefore the framework of cultural competency must be included in an expanded framework of care, if the health practitioner is to meet the goal of health care, the improvement of quality of life for the patient.¹³¹

The realization of an expanded view of care is fostered through the lens of cultural diversity, specifically by applying the Georgetown health care framework and the Global bioethics framework, which heretofore has been absent from the FGC discourse.¹³² The cultural

practice of FGC is extensive in Africa. However, there are communities of women and their families now living in the U.S. The current reality is that FGC is being done in the U.S., particularly in New York, and in Boston.”¹³³ Many women who have had genital surgeries embrace it as a procedure for cosmetic beautification not unlike western women. For example, the US cosmetic surgery obsession and the globalization of the images of women’s bodies has increasingly popularized the ideals of a smooth and clean genital look that is reminiscent of the aesthetic standards associated with FGC surgeries. One example is labiaplasty done by cosmetic surgeons in the U.S. and Europe. The globalization of FGC and the increase of women experiencing the medical intervention is an indication that FGC is not going away.

An expanded and inclusive model of care honors the uniqueness and complexities of particular other, specifically, an individual’s refugee status, culture, ethnicity, and the autonomous choice to undergo a practice in a society that often knows little about FGC. It includes respect for cultural diversity. Respect for cultural diversity is the lens by which the cultural custom is viewed less negatively. Since the right of people to participate in their culture is a human right, respect for cultural diversity and pluralism is fundamental to the inclusive and expanded model of care for women experiencing FGC surgery. All of the elements and characteristics of culture also called sociocultural features have unparalleled influence on health decisions. For example, as it concerns ethnicity, women choose FGC to indicate they belong to a particular community or tribe. In addition, FGC is intimately associated with marriage. To honor these features of refugee women who choose FGC surgery, the moral qualities of care are realized. These moral qualities of care, attentiveness, competency (cultural), responsibility and responsiveness are interconnected and part of the holistic construct of care,¹³⁴ and they must be included in the new construct of care for women experiencing FGC.

Therefore, harm reduction and medicalization play a significant role in the new model of care for women experiencing FGC and are included. Frankena's framework of beneficence, which includes non-maleficence, is applicable in the model of care. Using Frankena's frame of beneficence allows for the use of harm reduction. Since there have been small successes made in the eradication of FGC and an increased suspicion that the occurrence of FGC in the US is more frequent than previously thought,¹³⁵ harm reduction is a worthwhile and credible response and must also be included in the model of care. Harm reduction, according to the Article 4 in the *Universal Declaration on Bioethics and Human Rights*, is morally acceptable as the idea of harm reduction is to minimize harm, particularly the alleged harmful consequences associated with FGC surgeries. It is the patient who determines not only quality of life but also what they view as harm. Since FGC is not going away, it is critical to include harm reduction in the expanded view of care. The idea of abolition is not the solution.¹³⁶

The medicalization of FGC is also a part of the new model of care. Medicalization is deeply associated with and connects to non-maleficence. In communities where culture is the dominant rationale behind the practice, medicalization can be "socially acceptable."¹³⁷ In fact the results of the research found that medicalization was being taken over by the modern health sector and as a result there may be very low circumcision related so called health consequences.¹³⁸

Concerning care, responsiveness necessitates attentiveness.¹³⁹ Responsiveness in the expanded view of care understands the needs of others rather than putting ourselves into their position when this is impossible to do.¹⁴⁰ Instead, consideration is made for the other's position, in the way that it is expressed.¹⁴¹ The attentiveness to the moral principle of vulnerability allows for paying attention to vulnerability. Since care is relational, it suffices that respect for

vulnerability, which is characterized by our common humanity, is a feature of care for women who choose FGC surgery.

In considering models of care, the theoretical-juridical model offers a moral guide that defines what is included when we care for others. Its counterpart, the expressive-collaborative model emphasizes the critical nature of attentiveness and responsiveness. The ethics of care embraces the activity of care. Most importantly in discerning what the model of care should be for women who undergo FGC surgery, the major feature and the central focus of the ethics of care is on the persuasive moral importance of attending to and meeting the needs of those for whom we take responsibility.¹⁴² In fact, it is an obligation to do so. Lastly, a model of care for women who experience FGC includes care in a respectful manner. Ministering care in a non-respectful way does not promote a positive outcome for the patient and cannot promote quality of life, the most fundamental goal of medical care.¹⁴³ Care includes doing so in a manner that is attentive, responsive, and respectful.¹⁴⁴

NOTES

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